

In Our Blood: Mapping Narrative Enactments  
of Leukaemia Online

A PhD Thesis

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of Falmouth University to the University of  
the Arts London as a thesis for the degree of  
Doctor of Philosophy (PhD)

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## **Abstract**

Often externally invisible, and currently considered incurable, chronic lymphocytic leukaemia (CLL) presents with variable progression outcomes from indolent, through actively progressive, to terminal in some cases. Diagnosed with CLL myself, and having learned much of what I know about my disease online, this virtual ethnography triangulates autopathographic narrative with object oriented philosophies to map digital narrative circulations relating to the disease. Observing that key CLL online support sites function as hubs within complex networks connecting through to a variety of narrative enactments of CLL, this thesis draws on Actor-Network-Theory (ANT) throughout to explore and explain these narrative phenomena. The work shows that stories relating to CLL circulate in differing forms across networks peopled with varied actors (both human and non-human artefacts), key among which is the informed, connected and empowered 'e-patient'. These digital actors mobilize a wealth of information from translations of the complex evolving science pushing the boundaries of biomedical understanding and treatment, to sharing the daily effects of living with a cancer whose sufferers record exceptionally low emotional well-being. By exploring the intersection of circulating narratives of a single disease online from a perspective of their material rather than representational effects, I locate them as inscriptions of the practices enacted by the individuals, organizations and institutions producing and putting them into circulation. In doing so, I argue that this study successfully puts into practice an innovative approach for studying disease and its narrative performances in online support and knowledge exchange networks, revealing complex networks of intersections among the multiple narrative inscriptions of CLL

online. The work identifies some of the key actors and narratives engaged in that process, demonstrating some of the network effects produced when they come together. Notable among the multiple effects generated through these complex assemblages of collaborative narrative circulation in online communities are changing patterns of knowledge exchange in clinical relationships, an over-arching potential for a variety of forms of patient empowerment, and the emergence of new open and generative forms of digital pathographies.

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Figure 50: CLLSA UK HEALTH UNLOCKED (2014) 'Julia's Story: from CLL diagnosis to a doctorate study of how people use the internet' [Video Screenshot]. [Online] Available at: <https://healthunlocked.com/cllsupport/posts/131147447/archive-of-latest-cllsa-videos> [Accessed 28/07/2015]. ..... 575

Figure 51: Panel discussion video published on 26 Jun 2014 [Screenshot]. [Online] Available at: <https://www.youtube.com/watch?v=9882LmKVMRc> [Accessed 28/07/2015]. ..... 576

## Acknowledgements

This work would not have been possible without the input of all the people with CLL (and their carers) whose experiences bring life to its pages. Due to the overwhelming response I received, I have not been able to quote each respondent who took the time to contribute, but I have carefully considered, and been influenced (and moved) by all of their stories in the process of writing this work. I would like to thank Nick York of CLLSA UK especially for his faith, support and belief in the project from the outset. I also want to extend a broader debt of gratitude to all of those people who contribute tirelessly to the exchange of CLL knowledge online, from global patient advocates featured in this work such as Jeff Sharman, Brian Koffman, Chaya Venkat, and the late Terry Hamblin, through those dedicated researchers and clinicians working to change the landscape of CLL treatment, to those patients who contribute so generously to the support networks explored herein and beyond. To Brian, Dylan, Jake, and Finn, I owe infinite love for enduring yet another colonization of the kitchen table by books/papers/laptop and my somewhat distracted academic evil-twin, during what has not been the easiest of times for us as a family. You keep me going. Huge gratitude is extended to Alan Bleakley, and Mike Wilson of course for being such generous, humorous, and supportive supervisors, and to Jemma Julian for such efficient and cheerful administrative support. Finally, a big thank you goes out to my long-suffering consultant haematologist for helping me stay above ground, and for so willingly accommodating the effects of my CLL research on our clinical relationship. The project continues....

**Author's Declaration:**

The work contained in this thesis is the sole work of the PhD candidate. The word count is approximately 96,000. This word count is exclusive of table of contents, abstract, bibliography and appendices.

## Abbreviations

<b>AIDS.....</b>	<b>Acquired Immuno-Deficiency Syndrome</b>
<b>AWMSG.....</b>	<b>All Wales Medicines Strategy Group</b>
<b>AZT.....</b>	<b>Azidothymidine</b>
<b>ANT.....</b>	<b>Actor Network Theory</b>
<b>ACOR.....</b>	<b>Association of Cancer Online Resources</b>
<b>CDF.....</b>	<b>Cancer Drugs Fund</b>
<b>CLL.....</b>	<b>Chronic Lymphocytic Leukaemia</b>
<b>CLLSA .....</b>	<b>Chronic Lymphocytic Leukaemia Support Association</b>
<b>CLLPAG.....</b>	<b>Chronic Lymphocytic Leukaemia Patient Advocacy Group</b>
<b>CML.....</b>	<b>Chronic Myeloid Leukaemia</b>
<b>EAMS.....</b>	<b>Early Access to Medicines Scheme</b>
<b>FCR.....</b>	<b>Fludaribine, Cyclophosphamide and Rituximab (chemotherapy regime)</b>
<b>FDA.....</b>	<b>Food and Drug Administration (US)</b>
<b>FPH.....</b>	<b>Faculty of Public Health</b>
<b>HCL.....</b>	<b>Hairy Cell Leukaemia</b>
<b>IOB.....</b>	<b>In Our Blood (refers to online survey conducted for this thesis)</b>
<b>IgVH.....</b>	<b>Immunoglobulin Variable region Heavy chain (now known as IGHV)</b>
<b>MDS.....</b>	<b>Myelodysplastic Syndrome</b>
<b>MHRA.....</b>	<b>Medicines and Healthcare products Regulatory Agency</b>

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**MRD.....Minimal Residual Disease**

**NICE.....National Institute of Clinical Excellence**

**OS.....Overall Survival**

**PFS.....Progression Free Survival**

**PIM.....Promising Innovation Medicine**

**RCHT.....Royal Cornwall Healthcare Trust**

**RCT.....Randomized Clinical Trial**

**SLL.....Small Lymphocytic Lymphoma**

**SMC.....Scottish Medicines Consortium**

## **Introduction**

### **In Our Blood: Mapping Narrative Circulation in Online Leukaemia Networks**

I am a former emergency and psychiatric nurse who graduated as a mature student in English and media studies, and moved into academia as a University lecturer specializing in the intersection between representations of crime, conflict, illness and trauma with new media technologies. On a late afternoon in March, 2011 I left work early to pick up the results of a blood test from my GP. Less than an hour later, I sat in his consulting room absorbing a diagnosis of chronic lymphocytic leukaemia. I was temporarily silenced by shock but as my voice slowly returned, key questions emerged about the disease and its likely impact on my future.

These are the answers I got. Chronic lymphocytic leukaemia (hereafter CLL) is currently considered incurable. It is treatable however. Its progress varies widely. Some people might die of conditions related to their disease within 2-5 years, whilst others might live twenty years or more. There was no way of knowing where I personally would sit on the spectrum of disease progression. It is, I was told, regarded a 'good' cancer due to its - often slow progression, and relatively manageable symptom burden in the early stages.

Although still the most common form of adult leukaemia (accounting for approximately a third of all leukaemias diagnosed in the UK) CLL remains relatively rare with an annual incidence in



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the UK of about 3.7 cases per 100,000<sup>1</sup>. Not all GPs are familiar with treating patients with the condition, and patients with a suspected diagnosis of CLL will be referred to a haematology consultant. My own GP was unable to answer the fundamental questions I asked as I struggled to absorb the implications of a shockingly elevated white cell count and the words ‘probable CLL’ printed on the test results he handed me that afternoon.

Played out daily in clinics and GP’s surgeries across the land, these are the quotidian moments that change lives forever. On the tails of lab reports such as this, the potential of imminent mortality comes shrieking into lives with all of its insistent, demanding questions. Its clamouring displaces everything. How long would I live? Would I need chemotherapy? What would life with CLL be *like*? My GP was sorry – he didn’t know what this would mean for me.

Acknowledging the dreadful paradox of so grave a diagnosis with so little information, he referred me to a haematologist, and advised me to go home and “*look it up on the internet*” in the meantime. Two mutually intertwined research projects began that day. The first, and most immediate, focused on the task of gaining the knowledge I needed to move forward and survive. Growing out of that came the second – this four year doctoral exploration of narrative circulation in online CLL networks.

Awaiting my first Consultant appointment, I followed my doctor’s orders with evangelical zeal, scanning the internet for all of the information I could find on CLL. I learned that most patients

<sup>1</sup> Figures pertain to 2011, and can be found at: Cancer Research UK (2012).

are fifty years old or older, usually male and often asymptomatic or mildly symptomatic when diagnosed, and most do not require immediate treatment. Some patients never require treatment, yet for others, an indolent phase evolves into disease progression indicated by deteriorating blood counts, increasing fatigue, frequent infections, and enlargement of the lymph nodes or spleen. When symptoms impact severely on quality of life, or become life-threatening in their own right, treatment is advised.

Chemoimmunotherapy (CIT) regimes have formed the 'gold standard' of CLL treatment for over a decade now, improving outcomes for many on the previous standard chemotherapy<sup>2</sup>. A subset of patients with particularly favourable genetic profiles still find themselves in remission up to twelve years following their initial treatment, leading to hopeful speculation about the possibility of a 'cure' in these cases. A significant number of patients relapse much sooner however, requiring subsequent rounds of further treatment. Currently, those requiring repeat cycles see diminishing returns and increased impacts from the significant toxicity accruing from CIT, and their disease eventually enters a terminal phase (assuming more serious secondary malignancies triggered by the toxic effects of chemo don't kill them in the meantime). I learned that currently, the CLL world is buzzing with optimistic accounts of a brave new world of molecular treatments and even potential cures, many of which are rolling out from trial to market across the globe. These have the potential to positively influence outcomes for current and future CLL patients. I also learned that translation from pharmaceutical research and

<sup>2</sup> In a randomized study of FCR versus FC alone, Hallek et al. (2009), concluded that 'FCR induced a higher overall response rate than FC (95.1 vs 88.4%) and more complete remissions (44.1 vs 21.8%; p<0.001). With the addition of Rituximab, Median PFS (progression free survival) extended from 32.8 mo for FC alone to 51.8 mo for FCR.

development to accessible prescription is a long-tail process rendering the discourses of hope and excitement chimerical for many currently suffering from CLL. This dissonance became frustratingly clear to me when it later transpired that my own CLL was not of the indolent variety.

In that early process of researching CLL online I was struck by the heterogeneous nature of a disease that kills some patients within months from diagnosis, leaves others alive and relatively well for decades, and presents a range of potential outcomes between these extremes. It seemed then (as it does now) that uncertainty is the only current certainty of diagnosis with this disease, and inconsistencies in levels of information given to patients, as well as approaches and access to prognostic testing and treatment are apparent. One certainty however was the drive among some CLL patients for collaborative exchange of information and experience. This was evidenced by the broad range of support sites, blogs, and user-generated content in relation to the disease, dealing not just in biographical narratives, but very clearly engaged with a broad range of information and discourses contingent on disease experience.

Although researchers are beginning to explore online communication and support in chronic illness generally (Fox, S. and Purcell, K., 2010), chronic blood cancer experiences are woefully under-represented. Given that CLL accounts for around a third of all leukaemias diagnosed in

the UK (8,300 altogether in 2009)<sup>3</sup>, this represents a significant gap in the literature<sup>4</sup>. Evans et al (2011) outline the negative psychological impacts of living with this “incurable, invisible, and inconclusive” disease, recommending widespread recognition of patient requirements for ongoing information (Evans et al. 2011:1). No work has been published to date on how this group mobilizes the internet to address their information and support needs, nor what can be learned from that about both living with CLL and the internet cultures of disease generally. Yet I was discovering that a vibrant exchange of knowledge and experience and the mechanisms that enable it remain largely hidden away in semi-closed online communities<sup>5</sup>. This work sets out to bring some of that to the surface where its potential range of impact might be broadened.

Throughout this thesis, I draw on Actor-Network-Theory (ANT) to explore and explain phenomena that I discuss. What ANT is, how it can be used as a theoretical framework, and the primary research methods that it draws on, such as ethnography, are explained in detail later. Here, I note that key CLL online support sites function as hubs within complex networks that connect through to a variety of narrative enactments of CLL. These stories circulate in differing forms across the networks. Such networks are peopled with many different actors, to draw on this word as used by ANT to refer to both human and non-human artefacts – those with CLL and

<sup>3</sup> According to the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (2012), in the US It was estimated that 16,060 men and women (9,490 men and 6,570 women) would be diagnosed with and 4,580 men and women would die of chronic lymphocytic leukemia in 2012.

<sup>4</sup> Two CLL health related quality of life projects were conducted in 2007, and 2008 recording dramatically lower emotional well-being scores for this patient group in comparison to both the general population, and people with other cancer types (Shanafelt, T. et al, 2007; Else et al, 2008)

<sup>5</sup> As Shani Orgad notes in her work on online support communities for women with breast cancer, the potential of online narratives to transform broader public debate surrounding serious illness is to a large extent restricted by the closed/semi-private nature of many online communities (Orgad, 2006b).

those without. Key among them is Tom Ferguson's<sup>6</sup> (2007) vision of the informed, connected and empowered 'e-patient' at work, tapping into and sharing a wealth of information from the complex hard science of a disease poised at a crossroads of biomedical understanding, to the daily effects of living with a cancer whose sufferers record exceptionally low emotional well-being (Shanafelt et al, 2007).

In an evolving model of medical citizenship where digital cultures are beginning to re-shape traditional dualistic roles of knowledge exchange between patients and their clinicians<sup>7</sup>, virtual narrative accounts of disease experience play a significant role in peer-to-peer and professional communication relationships. We are witnessing a powerful revolution in the hegemony of medical knowledge production/consumption, at the heart of which sits Ferguson's "well-wired patient" (Ferguson, 2007). Here, 'patient-centredness' is being reconfigured as 'patient-connectedness', and both patients and clinicians alike must work on reconstructing traditional identities. Part of that task involves understanding the complex networks that the experiences of disease are meshed into and that, arguably, the internet has made more immediately visible and accessible. Online narratives speak of multiple disease experiences from multiple actors and their traces and intersections can be effectively mapped.

<sup>6</sup> US physician and writer Tom Ferguson envisioned a medical democracy enabled by the internet in which 'e-patients' feature as "individuals who are equipped, enabled, empowered and engaged in their health and health care decisions". For the fifteen year duration of his struggle with multiple myeloma ending with his death in 2006, Ferguson promoted health care as an equal partnership between e-patients and health professionals and systems that support them (e-patients.net, 2009 ).

<sup>7</sup> This e-democracy mirrors a wider call for the democratizing of medicine through medical education, including patient involvement (Bleakley, Bligh and Browne, 2011; Bleakley 2014).

Patient narratives of CLL online are networked into a complex mesh of social, political, economic, and cultural threads – connected by global systems of information exchange, yet grounded in local contexts of health care delivery, disease management, and personal experience. As my own story became enmeshed in these complex networks, I began to get a sense of the many actors involved in bringing a disease into being: connecting our blood cells to lab technologies and scientific research; relating clinical treatment decisions to the pharmaceutical industry, its investors and regulators; linking governance of local health care delivery to political economies; relating all of these aspects (and more) of our disease to the information technology that enables their (and our) various narratives to be shared; and acknowledging the cultural attitudes that frame the stories we tell each other and ourselves about disease. These are the ‘circulating’ elements across networks that ANT describes and that frames a new kind of phenomenology, where ‘actors’ – whether artefacts, ideas (ways of thinking) or persons (ways of being) present themselves in differing forms according to context and thus remain relatively unstable. Understanding such actors (epistemology) is secondary to appreciating their varied appearances (ontology). Where these appearances are written or talked about within networks of symptoms and illness, this is usually referred to as ‘illness narratives’ or ‘pathographies’.

The production and study of illness narratives or pathographies is a rich scholarly field in its own right pre-dating internet communications by many years. The varied montages of narrative objects circulating in online health networks however defy the kind of generic certainties required to pin down what we define as “illness narratives” in the traditional literary sense

(biographies, short stories, poems, journals and so on). Time spent in digital narrative networks also makes it clear that digital pathographies begin to defy traditional binary models of 'evidence-based' *versus* 'narrative-based' medicine in which the latter is located as demonstrative acts of individual agency set against the de-personalizing institutional medical gaze of the former (Riessman, 2002; Bell 1999; Langellier 2001). With their ongoing and unfinished nature, resistant to generic containment, digital illness narratives become an "amalgam of literary and non-literary forms, including autobiography or biography, journal, and medical chart"<sup>8</sup>(McLellan, 1997: pp100-101). In this thesis, I suggest that we add scientific research papers, international medical conference proceedings, medical education sites, news, social media, and popular cultural artefacts to the amalgam. I also ask how CLL pathographies online might be read as evolving forms of health narratives that, with their collaborative and hypertextual nature, often present as an accretion of multiple practices and motivations. My aim here is not to produce a schism between traditional illness narrative approaches and digital forms. Instead, I want to offer a view of an evolving form of pathography open to new possibilities in line with evolving forms of identity and technocultures *per se*, contextualized by the changing relationships between medical professionals and patients, and by a re-consideration of narrative form in an information culture.

Walter Benjamin has argued that: "narrative could not survive the moment of information" (1992: 73-89). This 'moment of information' can be read through the rise of database culture

<sup>8</sup> Faith McLellan (1997) defines the digital health narrative as an "unruly text" in comparison to more traditional literary forms of health writing which, although open to interpretation, are in some sense 'finished' and contained by their singular completeness.

which, it is suggested, can in itself be read as symbolic of life in Lyotard's "computerized society" (1979). 'Database' in this context is seen by Manovich as an organizational cultural framework in a postmodern vacuum of grand narratives into which has rushed "an endless and unstructured collection of images, texts, and other data records" (Manovich, 1998:2). The urge to develop a poetic, aesthetic and ethical framework for the database appears to be strong however (*ibid*). Narrative forms threatened on Benjamin's terms may evolve into new communicative practices that retain the imaginative alongside the informational, and that might lend themselves to less hierarchical modes of production, access and exchange.

Bassett (2007) suggests that information-pervasive new media forms operate as complex, multi-layered assemblies (both temporally and spatially) challenging traditional linear notions of narrative:

Narrative, understood as an extensive arc constituted by a process of emplotment that both reaches back into the horizon of the event and forwards into the horizon of the reader, can make sense of these experiences through a form of assembly that is not retrospective but in process, not necessarily linear but rather expansive, and that is certainly open and indeed *generative* (Bassett, 2007:3).

Narrative is presented here as "an intrinsic part of a new informational economy which becomes its material and which it holds and articulates" (Bassett, 2007:3). "*Which it holds and*



*articulates*” is the important point here in relation to my own work.

So, does the contemporary illness narrative encountered online demonstrate the ability to assemble the more informational narratives in the CLL network into its fabric in the expansive and generative way suggested by Bassett? I believe so, and through a process of mapping the connections and intersections of a range of circulating narratives online, this work sets out to test that hypothesis.

It is through my interest in the material effects of *multiple* narratives of a nominally singular disease coming together, that I draw for my methodological design on the ontological politics of disease proffered by scholars such as Annemarie Mol in her (2002) ethnography of atherosclerosis, and John Law and Vicky Singleton (2004) in their work on the multiple sites and enactments of alcoholic liver disease. As a CLL patient myself, my autopathographic narration is positioned as just one of many narrative dimensions in the network<sup>9</sup>, but an important political element of the research nonetheless, bringing an inside–out perspective to this ethnography of CLL online<sup>10</sup> that also offers credibility and veracity. In crafting a method that assembles the nuanced mapping of material relations of narrative enactments online, among which sits my own unfolding narrative of living with disease, I hope to create productive intersections between my own narrative enactments of CLL (of which this entire project is one), and a range

<sup>9</sup> Positioning my own narrative as just one object in a network accords with the ontological politics of the project, and as such addresses the critique of visibly incorporated subjective experience in ethnographic work as mere self-absorption, and what Geertz (1988) has disparagingly referred to as “author saturated texts”.

<sup>10</sup> This is designed in line with a reflexive ethnographic approach that “fully acknowledge(s) and utilize(s) subjective experience as an intrinsic part of research” Davies (1999: 5).

of other enactments that shape my own. By inserting my own narrative enactments into the mix as a 'native researcher' (Ellis, 2004; Denzin and Lincoln, 2008), my initial aims were at once to write from the centre of my experiences and from the margins of a culture in which the diseased, the sick, the dysfunctional are so often spoken *for*. But it soon became clear that my own experience may be de-centred by others, and that I can't talk uncritically of 'margins' and 'centres' if I accept the flattened ontological landscape of circulating narrative objects, of which I am just one. It is perhaps more fruitful to use my insider status to try to trace the network patterns that keep some actors more strongly tied into positions of control in some enactments of disease than others, and to ask if they might be changing in this new era of digital patienthood. Although an auto-ethnographic presence is very clear in this work, I make every effort to present it as just *one* narrative force in a field of many others I have encountered.

Mol (2002), and Law and Singleton (2004), whose work has been fundamentally influential on my own methodological practices, were located very differently as researchers observing day to day physical practices in the field – clinics, laboratories, waiting rooms and so on – and not having declared a diagnosis with the diseases that formed the object of their inquiry. My work, as a CLL patient-researcher, is situated with narrative practices of disease situated in a virtual field. I am observing the circulation of virtual texts, inscriptions, and stories that signify the material enactments of a disease. That raises an interesting methodological question about the object of study: in a virtual world where all that exists of a disease (or any entity) is textual, do those texts become digital 'objects' in their own right rather than merely inscriptions of 'real-world' practices? ANT would suggest so, offering such virtual enactments the same ontological

status as the 'real' (Latour, 2007).

Multiple enactments of disease (or any phenomena) online have to be read at once as separate from the everyday situated practices of doing disease offline and intrinsically related to them. The virtual CLL networks explored here become the digital archives and mediators of inscriptions produced on the ground (research papers, newspaper reports, policy documents) for sure. But they are more than just databases of informational narratives. These narratives are actively mobilized into support networks. They are circulated and shared by key actors. They come into contact with each other and with the online narratives of other human actors in the networks (primarily CLL patients and their carers). They are put into dialogue with narratives *specific* to the online support community – the shared stories of experience that CLL patients exchange in these networks daily. They begin to produce *network effects*.

I want to suggest then that when the inscriptions and narratives of institutional disease practice are put into circulation with patient narratives online, a potential for enacting offline practices of disease differently is catalyzed. Where productive narrative network effects are effectively mobilized into the everyday analogue practices they relate to, change might happen. The questions this work needs to ask then are primarily: What are these narratives? How do they circulate? *Who or what* does the circulating (that ANT refers to as 'translations')? What, most importantly, do they tell us about the concerns of those living with and treating CLL and the potential of online narrative circulation to address them?

There is already a vibrant body of work exploring issues of patient empowerment through online communities of illness that are fundamentally concerned with the potential of narrative sharing to effect meaningful change in the way people approach illness. Mette Hoybe and colleagues (2005) for example identified three different modes of action through which women in online support communities confronted breast cancer:

*“verbal acts of writing and communicating experience; imaginative acts, embodied in metaphors, re-imagining their experience of the world and regaining power over a life that was shattered by breast cancer; and, finally, practical action for withstanding cancer treatment, nursing the body through diets and exercise and educating themselves about their disease”* (Hoybe, 2002, cited in Hoybe et al., 2005:217).

The potential for such communities to fulfil a range of needs for cancer patients through varying narrative enactments is clear. In Hoybe and colleagues' respondents, the practices of crafting and imagining responses through attention to the communicative act of writing itself sits firmly alongside the practical necessities of communication purely as information exchange. Benjamin's anxieties seem for the moment unfounded. It would appear that the informational does not necessarily exclude the narrative drive. We are, it seems, not easily inclined to expunge the poetic from the database.

Like a good deal of the work in this area, Hoybe and colleagues take as their object narrative practices in a *specific* online community. This kind of focus contributes much to a fine-grained

understanding of very local communities of online narrative practice that may be extrapolated more broadly. In identifying these modes of action, Hoybe and colleagues aren't concerned methodologically with the narrative flows, intersections and enactments that underpin them – it is not their object of inquiry. Currently, there is very little research to be found on online support communities that wants to take on that mapping process.

There is probably good reason for that. It is a laborious process, and some may say too 'flat', too concerned with the metaphysical ontology of narrative objects and network flows to make a difference to the lives of those living with disease<sup>11</sup>. I hope I have already demonstrated why I think it matters that attention is paid also to the *complex networks* emerging from the intersection of a range of narrative forms and themes amongst a variety of actors enacting CLL online<sup>12</sup>. By mapping the narrative distribution of CLL online, I want to reveal what might be

<sup>11</sup> For a critique of ANT methodologies see A. Saldhana's (2003) Essay 'Actor-Network Theory and Critical Sociology', in which he reviews the following ANT texts: Law, J. and Mol, A. (Eds.) (2002) *Complexities: Social Studies of Knowledge Practices*; and Law, J. (2002) *Aircraft Stories: Decentering the Object in Technoscience*.

<sup>12</sup> What interests me particularly are the various interpretations of textual form either as a representational practice within the linguistic field, or as more Deleuzian interpretation of culture as a material force in which text operates as just one actor in a broader network, and is not regarded as a privileged locus of meaning in its own right. As Caroline Bassett points out, "...here the cultural text itself, the narrative, is not to be explored in terms of representation but in terms of how it performs, acts upon us, or materially produces an effect" (Bassett, 2007:23).

learned from a broad, heteroglossic landscape of multiple actors and objects. Part of that may involve exploring the inscriptions that maintain dominant forms of disease definition, and asking if or how 'e-patienthood' is enacted to *challenge* the discursive power of those inscriptions. Importantly though, I want to explore how people with CLL *translate*, *accommodate*, *re-iterate* and *re-define* the multiple narrative enactments of CLL online.

In her observations of the unfolding digital narrative written by the father of a boy undergoing treatment for acute lymphocytic leukaemia, Faith McLellan (1997) describes digital health narrative as ongoing, unfinished and unruly texts with the potential to reveal valuable information about experiences of illness not accessible through the arguably more singular and self-contained narratives of the print form. With their mix of lab reports, journal entry, existential observation, requests for advice, experiential accounts, demonstrations of medical and scientific knowledge, links out to relevant sites and information, and responses to comments from other forum users, digital health narratives are potentially at once heterogeneous and collaboratively heteroglossic accounts. This raises the potential for individual narrative reconstruction online to become an ongoing reflexive project, drawing on and sharing a range of resources that is by its nature collaborative, multidisciplinary, and dialogic.

As well as seeking to fulfil the function of getting presently “hidden” voices out into the public domain, this project is concerned with exploring how those living with CLL and their carers are *themselves* enabled or empowered (or otherwise) through online narrative interaction surrounding the disease. Tom Ferguson concluded that “The art of ‘empowering’ patients is trickier than we thought” (Ferguson, 2007:23), noting that “clinician-provided content has few, if any, positive effects” (*ibid*, 24) where the patients’ own level of engagement with their illness has not undergone significant change.

My aim to map the multiple contextual stories that touch the individual stories of people living with CLL online acknowledges that a disease is always experienced as the combined forces of a *number* of practices and interests. By mapping patient stories and the broader interests that shape them, I suggest we can achieve several things: We can identify the key players and activities involved in holding a particular disease together as a single entity; we can identify the major concerns of those living with the disease; and we can perhaps begin to think about strategies for bringing the different enactments of a disease into more productive alignments.

Diagnosed with a chronic cancer at these crossroads of knowledge and communications technologies then, I am well located to map the new territory as I negotiate it as native and as researcher through both insider ethnography and reflexive auto-ethnography. Triangulating ethnography and auto-ethnography with Mol (2002), and Law and Singleton’s (2004) ontological interpretation of ANT, this exploration of CLL online asks how multiple narrative objects circulating online translate to the lived realities of this form of leukaemia. Whether

patients talk of changed relationships with their doctors, efforts to access trials and drugs, or the understanding of developments in CLL knowledge and treatment behind statements such as “I no longer have the sense that I have a sword of Damocles hanging over my head....” (*In Our Blood* survey respondent 25), this work sets out to map those effects.

What can we learn about the various ways in which CLL is “done” to patients, and the way that those patients “do” this chronic blood cancer in an embodied, digitally connected, and increasingly genetically decoded world? What are the implications of digital narrative exchange for an unfolding philosophy and anthropology of illness in a new bio-medical and technological landscape? This PhD sets out to address those questions through the aims set out below, and the following chapter outlines my methodological approach to that challenge.



## **PROJECT AIMS:**

- To explore and map the evolution of patient illness narratives as they move into circulation with a range of other narrative enactments of disease online.
- To locate and map the networks within which multiple CLL narrative enactments circulate and intersect online, identifying key nodes and actors.
- To make visible the key themes and issues faced by those living with CLL through mapping narrative themes online.
- To reveal the major points of intersection of the various narrative enactments identified, highlighting synergies, tensions and obstacles in the bringing together of multiple enactments of CLL online.
- To utilize and adapt object-oriented methodologies for mapping online narrative networks and flow.
- To design a methodological approach for writing up multiple narrative enactments in a way that prefigures the ontological politics of the project.

In the following chapter, I set out *how* I addressed these aims through choosing a methodological framework and then related research methods.

## Chapter 1: Methodology

*“A reader, asking in what sense our theory of the social could be reconciled with ‘conventional’ sociology, offered as an objection the way AIDS patients mobilized as a group. Looking at traditional ‘social movements’ it was obvious to her that patients’ organizations corresponded to ‘conventional’ definitions of the social because she had entirely forgotten how deeply innovative it was for patients to make politics out of retroviruses. For us on the other hand, AIDS activism and, more generally patient-based organizations, is just the type of innovation that requires completely new definitions of the social”*

*(Latour, 2005:23)*

### Introduction to Methodology

As set out in the introduction, this project was borne of a personally motivated interest in opening/illuminating the black box of CLL as a single knowable disease to reveal at least some of its varied versions and their connections. I was struck by the complexities and multiplicities of narrative manifestations of CLL I found when I followed my doctor’s orders to ‘look it up online’. I was diagnosed with CLL yet could find no single CLL to which I could relate my own experiences. Instead, I encountered various versions of the disease circulating around online networks of varied actors (persons, ideas and artefacts).

Discrete nodes of interest meshed into a broader network of CLL communications. For example, information on drug regulation and funding from the NICE site finds its way into individual

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stories surrounding access to new CLL drugs in support communities. Research papers from online journals revealing a panoply of new treatments and approaches to CLL circulate from clinicians and scientists to patients and then in conversation to family members and friends. They move across online networks alongside multiple inscriptions of CLL from graphs of prognostic curves predicting average survival times, news stories trumpeting miracle cures, documents outlining healthcare policy, and advice from dedicated support sites, finding their way into interactive forums hosting multiple individual narrative enactments of living with a CLL diagnosis.

CLL-specific networks buzz with a vibrant energy borne of strong links and associations, and connect out into broader, diffuse networks in all manner of pathways by weaker links. These CLL 'hotspots' unite (non-human) technologies enabling online interaction with a range of (human) actors distributing multiple narratives of CLL across key nodes, also linked strongly and largely manifesting as support groups, advocacy sites, and patient or patient/physician blogs. Key to this work is how such narratives intersect in ways that not only make visible the tensions of 'othering' upon which each enactment to some extent depends, but are productive of effects that move to disrupt the 'othering' process through narrative amalgamation.

I am arguing here that online narrative sharing allows for those caught up in particular modes of disease enactment to consider the effects of absorbing 'other' narrative enactment of a disease into their own. Drawing on the work of Gilles Deleuze and Felix Guattari, we might say that these circulating narratives have the potential to de-territorialize and re-territorialize each

'other'. Further, such territorializing work is often reported in the genre of travel writing replete with adventure, discovery, new horizons and cross-cultural exchange. Drawing further on Mikhail Bakhtin's ideas, there is less and more coherent dialogue at every point as a polyphony of voices – continually challenging medicine's quest for certainty (Bleakley 2015).

I began this methodological journey favouring a traditional ANT approach which would allow for defining networks, identifying particular 'network effects', and tracing the involved actors (persons, artefacts and ideas given equal ontological status); translations ('conversations' between actors that potentially expand a network); intermediaries (actors involved that do not promote translation and then expansion of the network but may keep the network stable); and mediators (actors involved that destabilize but expand the network, working against crystallization and collapse). This is important if a) we believe there is a value in harnessing the knowledge gained to underpin effective system design that might enhance that potential; or b) we are more broadly concerned with making visible how people in a digital era 'do' disease (or both). This project doesn't lean *primarily* towards drawing inferences about system design, although the findings may help inform effective online networking. It is more concerned with mapping ways in which particular narrative enactments of disease online might come together in networks productive of change. One of the driving tenets of this work is a conceptual shift from patient centredness to patient connectedness in which patient groups may provide labile nodes in a system rather than stable centres. Making visible the range of narrative practices and enactments behind that requires a bigger lens than the traditional sociological binary

biomedical gaze *versus* patient perspective, as Law and Singleton point out:

Arguably if attention is directed to enactment, then the opposition between biomedicine and the patient perspective dissolves, to be replaced by studies of specific practices that create complex bodies and subjectivities which do not bifurcate along this join (Law and Singleton, 2003:11).

The methodological evolution of the project has taken me from Latour and Callon's earlier ANT approaches to the ontological turn informing Law and Singleton's (2004) work on broadening out the range of object possibilities in their work on liver disease (particularly their concept of 'fire objects') and, most emphatically, Mol's (2002) approach to making visible multiple enactments of a putatively single disease object<sup>13</sup>. Further contexts for these concepts are explored in the first Perspective section of this chapter.

While this work aims to locate and map the networks within which multiple CLL narratives circulate and intersect online, identifying key nodes and actors, it is about much more than seeking to reveal process. In line with another of the project aims, I set out to make visible the key themes and issues faced by those living with CLL, to understand and reveal the major

<sup>13</sup> For instance doctor and ethnographer Annemarie Mol has shown for lower limb atherosclerosis how different sets of relations in (for instance) the general practitioner's surgery, the haematology laboratory, the radiography department, the physiotherapy service and the operating theatre each produce their object – the atherosclerosis in question. (Indeed it is more complicated than this since there may be differences between these objects – a point which we will come back to shortly) (Law and Singleton, 2003:4)

tensions and obstacles that might exist in the bringing together of multiple enactments of a single disease, and to identify areas where they may be intersecting productively or otherwise. The following short subsection describes how the chapter is structured to map the methodological decisions taken to meet those aims.

### **Negotiating Method: Questions of Site, Self, Ontology, and Ethics**

Concerned as it is with mapping multiple narrative enactments of a single disease, the issue of site was the primary challenge in designing a method for this project, and will be addressed in detail in this chapter. Not least among the considerations of site, is that of my own role in the work as an insider researcher living with CLL. Decisions about how to merge auto-ethnographic approaches with the object-oriented approach with which I have chosen to frame this work are outlined in the chapter, as are ethical considerations surrounding gathering data from a potentially “vulnerable” subject group, of which I myself am a member. Finally, the chapter both explores and exemplifies my approach to writing up the work in a way that prefigures its ontological politics.

These key (interdependent) methodological themes are set out as separate issues in sub-titled sections. In line with the project’s aims, the work is structured to layer relevant ‘perspectives’ or contextual work from existing literature, with examples, or ‘translations’, of circulating narratives presenting multiple enactments of CLL online. The philosophy behind textually

layering multiple narrative versions of CLL is explored later in the chapter, although I outline the practice briefly here for clarity. 'Translation' sections set out to map key actors, nodes and mediators under the overarching theme of the chapter title. They allow for showing what discursive, institutional, and individual narrative enactments of CLL can be traced across the nodes, and then what networks can be identified. They reveal what knowledge, practices and change (acts of resistance/evolutions/becomings) might be produced where they intersect, and contribute to showing who or what drives the flow of these narratives around the CLL networks online, and what we might learn from them. In this Methodology chapter, the approach is used to map the evolution of this project itself as a network, as an enactment of CLL, and as the product of a range of texts, technologies, discourses and subjective experiences in its own right.

'Perspectives' sections allow for a consideration of some of the relevant literature or existing work in the field in relation to the themes identified, and Translations selected. These are intended to provide a diverse range of theoretical practices and institutional contexts surrounding the subject matter, and to populate the richly detailed map of connections I am aiming for.

## **Perspectives: Multiple CLLs across Multiple Sites**

AnneMarie Mol trained as a doctor in the Netherlands but chose to become a medical anthropologist and ethnographer and then developed her work as a philosopher informed by radical feminist perspectives. In her radical ethnography of atherosclerosis, *The Body Multiple*,

she painstakingly identifies the fragments comprising a “whole” disease, mapping the networks of objects and activities that make it cohere, whilst always acknowledging that discursive networks do not expunge physical reality: “patients may interpret bodies, but they also live them” (Mol, 2002: 20). Readers see a disease take shape that is “both material and active”, made up of activities, experiences, interactions, texts, objects, conversations, drugs, incisions, scars, and stories (*ibid*).

Mol’s work draws on the intrinsically Foucauldian object-oriented ontologies of Actor-Network-Theory (ANT) developed by Bruno Latour, Michael Callon, and John Law. ANT is concerned with how different objects come together in various ways within networks to produce what appear to be complete technologies, knowledge forms, and ‘accepted scientific truths’ (Bassett, 2007: 84). These ‘finished’ ways of knowing are understood to emerge from practices of *mediation* and *translation* through which objects may appear in many forms. Latour describes the initial blueprint plans for Paris’s proposed high-speed rail network Aramis, for example, through the design and political issues that dogged it, to its ultimate abandonment and translation to rust (Latour, 1996). Here, a network was promised, potential translations showed, but intermediaries rather than mediators (for example blueprint designs did not match the realities of actual engineering possibilities) dogged the project so that a network failed to materialize. The human and non-human presences in the network are regarded as symmetrical in their potential to mediate and translate (but not substitute) objects. The ontological politics (how existence of objects or actors is also a network of power relations) lay in the exploration of the factors contingent on keeping the object or knowledge recognizably consistent as it translates



across different modes. This is not about tracing ‘truth’ and its ‘representation’, but about understanding how the processes of mediation producing ‘truths’ can be seen as ‘productive and constitutive’ at different sites (Latour, 2000, cited in Bassett, 2007: 85). It is in this acknowledgement of multiple sites that a number of questions concerning my own research design emerge.

### **Defining ‘Site’**

Site in this work could be myself; the narratives and texts I encounter; the condition as it appears through the narratives; the communities that emerge around these narratives; or the technologies that enable their presence on the internet, which could include its own subsets of computer technologies, biomedical technologies, and technologies of the self. A clearly defined, encapsulated site is difficult to delineate in this case as all of the above intersect variously to produce CLL(s) online. CLL shape-shifts across and between all of these sites (and more). Hine echoes this when she warns that: “When a technology appears to offer up a clearly defined field site...these sensibilities suggest that one should become suspicious” (cited in Markham and Baym, 2009:4). Mol similarly observes: “blow up a few details of any site and immediately it turns into many” (Mol, 2002:51).

A clearly defined research *object* itself is no easier to pin down. Law and Singleton’s (2004) description of methodological struggle in their ethnography of alcoholic liver disease

demonstrates this 'slipperiness':

...we slowly came to believe that we were dealing with an object that wasn't fixed, an object that moved and slipped between different practices in different sites...This was an object that, as it moved and slipped, also changed its shape (Law, 2004:79).

In other words, alcoholic liver disease was performed differently by different (or possibly the same) people in different places. Mol says that diseases then are 'done' (Mol, 2002). Rather than tangible things inside bodies subject to a range of different perspectives, diseases are enacted into social being through multiple practices across multiple sites that coalesce (or not) in relatively stable networks through processes of coordination, translation and distribution. Method quite simply "never isolates these [diseases] from the practices in which they are, what one might call, enacted" (Mol, 2002: 33).

A conceptual shift is required to circumvent the widely-held concept of an internal/external (subject/object) binary in which an objective 'reality' exists 'out-there' beyond us and invokes all manner of representational acts 'in-here' that relate to it. (Law, 2004:160). Alcoholic liver disease operating at the site of textbooks enacts the condition as a complex set of "aetiological, environmental, physiological, anatomical, and behavioural relations and effects which match the statements in the text" (Law, 2004:71). These textual inscriptions become sites of primary definition for our understanding of disease, the 'in-here-ness' that represents its 'out-there-nesses. Interacting with the sites of this particular methodological assemblage (medical

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knowledge, training, and institutions) we are diagnosed, staged, treated, monitored, and (sometimes) discharged. The chronically ill enter a lifetime of monitoring, measuring and testing practices in which the body is read against the accepted inscriptions of “knowing” disease. There are inscriptions of disease knowledge outside of medicine too. Anyone who is or has been ill understands that its effects radiate out far beyond the body into a range of societal practices. Diseases are enacted at all manner of different sites, both within and beyond the body, and I am indebted to the work that has informed my approach to CLL in this way.

There is a departure though - both Mol (2000) and Law and Singleton (2004) worked in physical fields (hospitals and clinics) to trace objects of disease (atherosclerosis and alcoholic liver disease respectively). My field is an online network of hubs, nodes and associations across which multiple *virtual* narrative enactments of this disease are distributed daily, raising the question of whether the technologically-enabled texts that make up the virtual become ‘objects’ in their own right and not mere digital inscriptions of offline practices? Virtual CLL networks archive, circulate and mediate the inscriptions of its offline enactment but they go way beyond repositories for information storage and sharing. Through active mobilization into support networks by key actors, these narrative enactments (or objects) jostle, clash, influence, and produce *effects*.

The beauty of an online ethnography of this nature is the potential to shift the lens from analysis of local nodes and metaphoric description to the chains of associations they are meshed into as metonyms, revealing how the macro can be reconfigured as a cluster of micro

enactments tied into each other through a complex chain of associations and translations. The objects of interest in my work are not these local sites or nodes *per se*, but their role in the distribution of various narrative enactments of CLL online. Currently, ANT influence in online knowledge exchange research remains relatively rare<sup>14</sup> and my hope is that this work might evolve the methodological field in some small way. It seems to me that while Mol and others so beautifully describe the complex sets of associations, enactments, and appearances for particular diseases in physical settings, the problem of translating disease experience across intersecting object boundaries requires meticulous *ongoing* attention so as to avoid inadvertently accounting for a disease as a metaphorical object/s, and thus undermining its tangibility as something that affects real bodies and the lives lived through them. This is perhaps more pertinent than ever when undertaking an ethnography of disease through the evolving virtual associations of online disease networks. We could do well here to heed Susan Sontag's warning that diseases treated as metaphors turns real bodily suffering into abstract symbolic capital. Imagining a disease metonymically however allows for maintaining an experiential/ ontological dimension<sup>15</sup> (the disease is real for all actors, from patient lab

<sup>14</sup> Fox and Ward (2006) triangulate ANT with Deleuzian perspectives in their work on attitudes of internet users to medical knowledge and technology in a range of health contexts.

<sup>15</sup> See also Munday (2011) for his interpretation of Jacques Derrida's metaphysics of language in relation to metaphor/metonymy. "For him [Derrida] it is not the case that there are truths to the world that are already there waiting to find words. Rather, language generates a metaphysics through its own workings, through the repetition of words in connection with other words. Meaning is only possible through interdependence, and there is no final stability. This is metonymic because meaning is generated through contiguity (where one thing touches another) and not through representation (where one thing stands for or replaces something else). (Munday, 2011:136) Similarly, Munday draws attention to Deleuze and Guattari's metonymic view of language as 'rhizomatic' - concerned with contiguities and intensities in and between languages rather than representations (*ibid*:137) - this allows for more nuanced concepts of the process of linguistic translation itself as a process of negotiating the contiguities that are "not exclusive to a home or target language but exist in endless chains that extend from one language to another" (*ibid*: 140). Much as my work here maps the translation of enactments of disease across boundaries through such chains of association and intensities.

technicians to suffering patients) in which many nodes of expression are possible, but they are linked. This places appreciation of the illness before explanation, as ontology precedes epistemology.

## **Networks and Bracketing**

Some explanation of the definition of 'network' in this project is required at this point. It can be used to refer in one sense to computer networks themselves - a generic spatialized topography enabling the flow or circulation of texts around an intensely and strategically connected cluster of nodes. These are composed of human and non-human actors in the model of an actor network, but I want to bracket the connections holding generic computer networks together, and focus on specific networks holding CLL online together (or not), such as support sites, blogs, institutions, inscriptions and the research project itself. This process of bracketing relies on both suspending (bracketing out or ~~striking through~~, a common practice in Derrida's account of deconstruction, as a way of suspending final judgement and considering surplus), and eliding certain network practices in order that others can be foregrounded for exploration. Carefully utilized and acknowledged as a reflexive methodological tool, it enables focused study. Unthinkingly, in everyday contexts, it is also part of how we ignore complex translations in order to configure easy and potentially reductive object relations.

For example, I subconsciously bracket the myriad technological, institutional, and human elements enabling advanced genetic profiling, such as the years of biomedical research, issues

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of funding, lab equipment and personnel involved, other prognostic methods that might produce different results, or may never have made it to market and so on. When I get my test results, indicating a 'bi-allelic 13q chromosomal 'deletion, I believe intuitively that the test has *found* that, and not produced or enacted it through practice. I know from reading the research that 13q deleted disease often progresses. By eliding all that sits behind the practices of prognostic testing and connects it to clinical implications, I can unproblematically read the results as one of a range of recognized indicators targeted at categorizing a common object of CLL that exists in my body. I can believe that I feel ill because, as doctors and technicians have attested, I have this particular genetic version of CLL inside me, and it is progressing as my tests indicated it might.

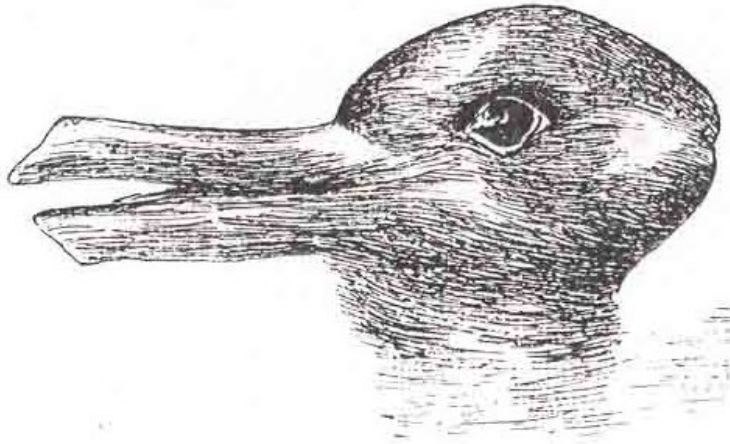
Is there a problem with thinking like that? Elision or bracketing is surely just shorthand for survival in a world where we don't have time to consider every connection that makes things happen. In terms of my CLL progression, the chromosomal abnormalities indicated its likelihood, a number of different blood tests confirmed it was happening, as would a bone marrow biopsy, and as did my swollen lymph nodes and spleen on palpation. The textbooks were right – the disease did progress as indicated, so it remains easy to imagine that the disease is in fact a singular object that can be known through tests and texts.

But is *it* actually there? A single entity in my body, made visible by these procedures? Or is it enacted differently in all of the different tests I have results for? Is it something a bit different in all of these? Might they even contradict each other, and if they do, then what is the tangible

‘truth’ of my CLL and where exactly is it located? Perhaps then there isn’t *one*? But working out how to hold multiple entities of a disease that one lives with requires some challenging conceptual work. It requires unraveling of our concept of objects as single entities occupying Euclidean space, readable from different perspectives, but consistent in their own right. It requires a refusal to accept disease as *singular* embodied pathological object subject to various external investigations. It requires thinking outside the body to explore the various practices that enact diseases and their connections. It requires thinking about how disparate practices and experiences might coalesce into a single disease.

How is my CLL, which has taken me to the edges of dying, necessitated toxic therapies, hospitalized me twice, requires lifelong three monthly clinic visits and blood tests, defines me legally in the workplace, affects people’s attitudes to me (and my attitude to myself), and denies me access to life and travel insurance, readable as a single object? Like most sick people, I think of myself as *having* CLL, the experiences I have directly related to my *being* diseased. Despite any conceptual effort expended on seeing things otherwise, I would never dream of telling anyone that I *do* CLL, or have it *done* to me. Yet it is an invisible disease for the most part. One doesn’t look at someone and immediately identify them as having CLL. Being relatively asymptomatic on diagnosis, the multiple narrative enactments I encountered online in the early days bizarrely *preceded* any real sense of actually *incorporating* the disease I was reading about. Prior to progression, it was perhaps easier to begin flipping the conceptual view of disease away from a primarily embodied singular entity to an unfolding ‘ontological choreography’ (Cussins, cited in Mol, 2002:43). So ingrained though is the socio-cultural frame

of the former, that it can still at times demand that we actively look for the rabbit in the duck or vice versa visually depicted in Jastrow's famous 'Duckrabbit' image shown in Figure 1 below (Jastrow, reproduced in Kihlstrom, 2004):



**Figure 1: KIHLMSTROM, J. F. (2004). Reproduction of Jastrow's Duckrabbit [Engraving]. [Online] Available at: <http://socrates.berkeley.edu/~kihlstrm/images/Jastrow/JastrowDuckRabbit.jpg> [Accessed 15/05/15].**

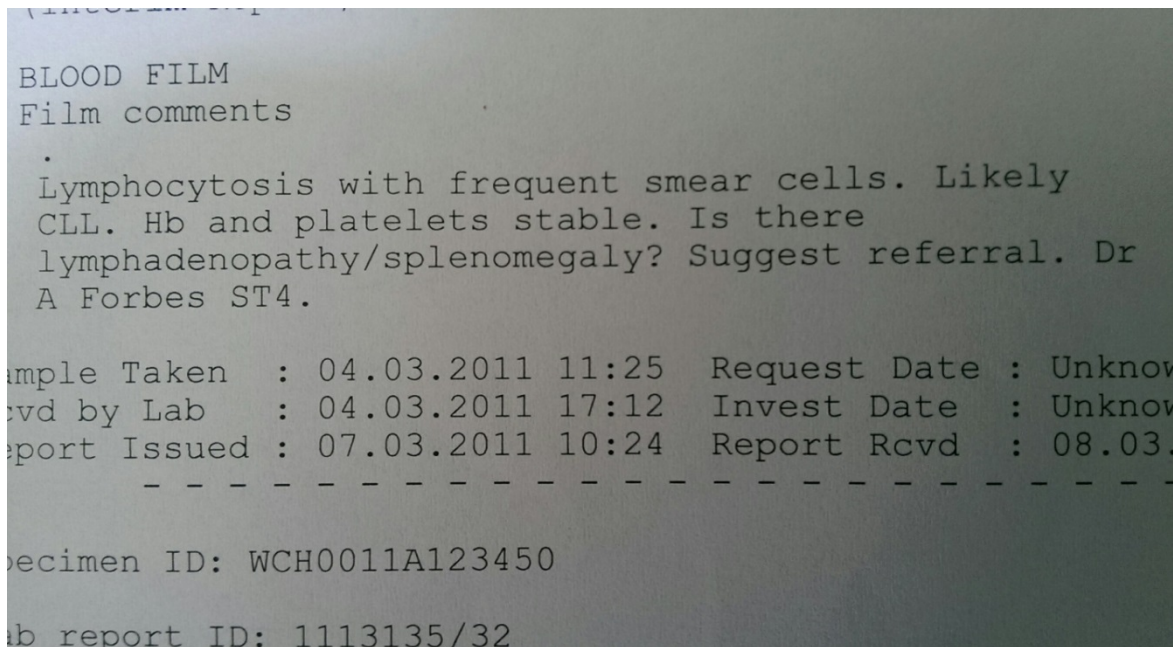
Once I could make myself *think* the objects of CLL as multiple and connected (a task far more taxing than holding together a two dimensional duck/rabbit in the field of vision), a decision still needed to be made about where to *start* with the process of mapping them. The following translation outlines my response to that challenge.



## **Translation: “Look it up on the Internet” (The Journey Begins)**

This project grew from my own experiences of trying to piece together the narrative fragments from various sites I encountered in the early days of my own personal research, ultimately ‘defining the argument’ of my ethnography. Driven to understand the multiple narratives of a heterogeneous, largely invisible, liminal yet potentially fatal disease in relation to my everyday embodied and disembodied experiences of it, I was already a multi-site ethnographer of CLL online from day one, concerned with the “chains, paths, threads, conjunctions or juxtapositions of locations in which the ethnographer establishes some form of literal, physical presence, with an explicit, posited logic of associations or connections among sites that in fact defines the argument of the ethnography” (Marcus, cited Gatson and Zweerlink, 2004: 180).

Far removed now from the familiar practice of trying to self-diagnose online, a blood sample taken from my arm a week previously translated to the fact that I was indeed very sick. No amount of Google second-guessing could trump the evidence on the lab report that confirmed this (see figure 2 below for a copy of the initial lab report). I *knew* what I had, or what it was called at least.



BLOOD FILM  
Film comments

Lymphocytosis with frequent smear cells. Likely CLL. Hb and platelets stable. Is there lymphadenopathy/splenomegaly? Suggest referral. Dr A Forbes ST4.

Sample Taken	: 04.03.2011 11:25	Request Date	: Unknov
Rcvd by Lab	: 04.03.2011 17:12	Invest Date	: Unknov
Report Issued	: 07.03.2011 10:24	Report Rcvd	: 08.03.

Specimen ID: WCH0011A123450  
Lab report ID: 1113135/32

**Figure 2: RCHT (2011) My Initial Diagnostic Readings, March, 2011 [Lab Report].**

This was the primary textual inscription of my disease, but now I had to decide where to go next... I needed to relate the numbers and acronyms on the lab report with me and the rest of my life. I tried starting with medical information. What is CLL? What are the 'smear' cells mentioned on my initial diagnostic lab report (replicated in Figure 2 above). Why is my white count so high? How does it progress and can I stop it? Why do people get it? What treatment protocols exist? What clinical trials are in progress? How is knowledge in the field evolving? I found medical education sites, open-source research repositories, and sites from organisations involved with cancer and leukaemia care.

Medical education sites were useful in the first instance, particularly in relation to translating the acronyms and terms used in lab reports. Sites such as Pathpedia.com, defining itself as a 'global pathology resource', and a 'unifying concept in pathology' describes its work online as:

...a comprehensive web-based resource on human anatomical, clinical, and experimental pathology. The site serves a target audience including pathologists, pathologists-in-training, laboratory professionals, clinicians, medical scientists, and medical students. The site can also be useful to general public who want to learn about human pathology and medical laboratory tests (Pathpedia.com, <http://www.pathpedia.com/AboutUs.aspx>).

*Pathpedia* was where I first turned to make sense of my initial diagnostic lab report, with particular reference to the term 'smear cells'<sup>16</sup> (otherwise known as smudge cells). Figure 3 shows a visual representation and textual description of smudge cells taken from the *Pathpedia* site.

<sup>16</sup> Smear cells, formed when the cell is disrupted during the spreading of the film, are characteristic of CLL, although but not pathognomonic (Bain, 2003)

Image removed due to copyright restrictions

[CHRONIC LYMPHOCYTIC LEUKEMIA, BLOOD]. B-cell chronic lymphocytic leukemia is the most common chronic leukemia in adults in Western countries. Most cases involve blood and bone marrow with or without involvement of lymph nodes, spleen, liver, and other organs. The neoplastic lymphocytes are small but slightly larger than normal small lymphocytes and show scant cytoplasm and round to slightly irregular nuclei containing clumped chromatin (three arrows). Nucleoli are small to indistinct. A characteristic morphologic feature is the presence of “smudge” or “basket” cells (two arrowheads) that are essentially neoplastic cells that got “smudged” during slide preparation because of the fragile nature of these cells. Compare the cell size of CLL cells with a single large granular lymphocyte (curved arrow).

**Figure 3: Pathpedia site reproduction slide and accompanying textual descriptor of B-cell CLL showing and describing smudge cells. [Reproduction laboratory slides]. [Online] Available at [http://www.pathpedia.com/education/eatlas/histopathology/blood\\_cells/chronic\\_lymphocytic\\_leukemia\\_\(cll\)\\_b-cell.aspx](http://www.pathpedia.com/education/eatlas/histopathology/blood_cells/chronic_lymphocytic_leukemia_(cll)_b-cell.aspx) [Accessed 12/04/2011].**

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Slowly, I constructed a picture of CLL at cellular level, as it infiltrates body systems, as it impacts on psychology, on the quality and length (see prognostic curves in Figure 4) of the lives of those who have it. Information was often dated, shaping my uninformed apprehensions with past prognostics. Similarly, narratives of hope for changing treatments and potential cure projected my understanding of and aspirations for the disease into an, as yet, only partially realized future. Then, as now, I suture together these temporally unstable fragments, unpicking and reweaving a delicate fabric of understanding as I go.

Image removed due to copyright restrictions

**Figure 4: MD ANDERSON CANCER CENTER. Survival of previously untreated patients with CLL, 1980-2002, classified by Rai stage [Graph]. [Online] Available at: <http://www.medscape.org/viewarticle/456068> [Accessed 03/12/11].**

Undoubtedly, things started to make more sense once I encountered support communities as hubs where these disparate narratives converged in the communications of *other people* experiencing CLL. That I was not alone in a small private hell (as it felt at the time) was a revelation. More useful still was the observation that these hubs forged multiple connections between medical, psychological, pragmatic, aesthetic, alternative, existential, employment-related, economically oriented, and social narratives surrounding CLL. Here I could lurk, post, ask, and learn about a multiplicity of narrative CLLs. I could map translations from one site to another. For example, what does the sophisticated prognostic testing made possible by advancing genomic understanding, and set out in the kind of research papers online shown in Figure 5 (see below), mean when it translates into probable disease progress for a member writing online? What will it mean for me?

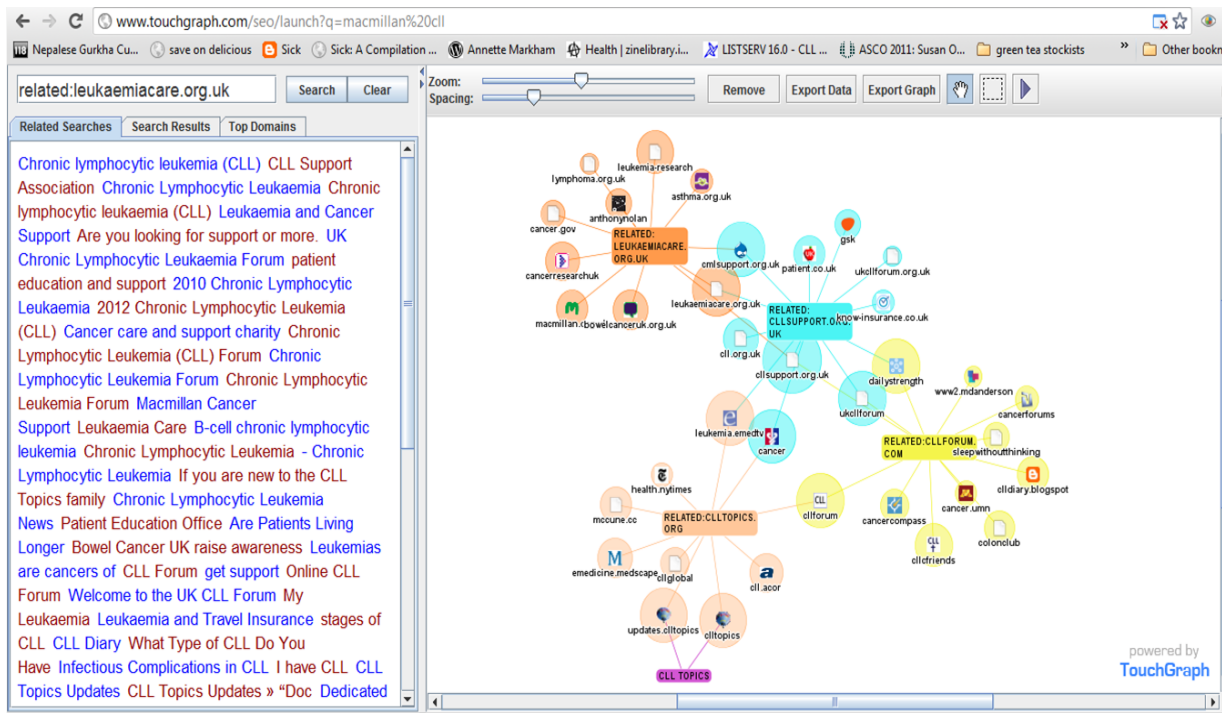
Image removed due to copyright restrictions

**Figure 5: BOTTCER (2014) 'Paving the Road to MRD-guided treatment in CLL' [Screenshot]. *Blood Journal* [Online] 123 (2) 4. Available at: <http://www.bloodjournal.org/content/123/24/3683?sso-checked=true> [Accessed: 12/05/2015].**

I cut my teeth on the US based ACOR dedicated CLL community (listserv), before finding the UK based Macmillan's CLL support group some weeks later. The Macmillan site interested me as a hub of collaborative connection between the multiple facets of CLL online, as a site where I could draw on Law and Singleton's observations concerning the multiple enactments of liver disease to bring CLL on the internet into hubs "in here", tracing the spokes to the rims "out there" (Law, 2004:160).

Mindful of Christine Hine's advice to maintain suspicion in the face of seemingly comfortably defined technological sites (cited in Markham and Baym, 2009:4) it wasn't my intention to view

this as my site *per se*, but as a point where various objects of CLL online come together through the community dialogue. The sites converging at this hub include support communities around the world, institutional and independent advice sites, research databanks, personal blogs, and health insurance information. The following three click network graph (Figure 6) taken from online network visualising software site TouchGraph shows just a fraction of the sites that connect to the Macmillan site<sup>17</sup>.



**Figure 6: TOUCHGRAPH (2012) network connections to Macmillan CLL site and related searches [Network map]. [Online] Available at: [www.touchgraph.com/seo/launch?q=macmillan%.20cll](http://www.touchgraph.com/seo/launch?q=macmillan%.20cll) [Accessed 24/11/2012].**

<sup>17</sup> Due to the semi-private nature of the disease specific groups on the Macmillan site, it was not possible to make the CLL forum the centre of the site, but the basic early stage network representation enables a visual overview of the kind of networks, and of the multiple interests and perspectives represented within a network concerned with a singular disease.



Each site holds potentially converging and competing versions of CLL and my aim is to identify how narrative versions of these are mediated and translated across key nodes. I am interested in *all* of the narratives enactments/narratives of enactment co-existent in the ongoing struggle to shape CLL. They sit alongside each other, add to or displace each other, intersect and interfere with each other in a number of ways. The ethos of multiple sites instilled from the outset has remained consistent, although the scope evolved as the human actors in my research network began shaping my design decisions as outlined in the following section. First, though, I have included a brief consideration of TouchGraph and its role as an important mediator for translating data in the project.

## **A Word about TouchGraph and other Software**

Throughout this work, I have used images from data visualization company TouchGraph to demonstrate connections and links between key nodes and the webs they mesh into. The services available allow for mapping links between URLs, subjects or authors entered as a search on the TouchGraph site<sup>18</sup>. Once the search object/s are entered, connections to related top domains are mapped as seen above. Data are also presented as a list of ‘related searches’ as shown above, a tabulated list of ‘top domains’, and the search results themselves with textual descriptor and URL (see Appendix 1 for expanded example). Largely a commercial product, aimed at companies wishing to access visual metaphors for their online networking, I

<sup>18</sup> The company describes their product thus: “Visualization goes beyond lists to reveal larger-scale patterns. Results are displayed in context – one can see how they fit into the big picture, how they relate to each other, and how they connect to metadata such as subjects and authors.” (Touchgraph, 2015)

have borrowed the basic free demo version to demonstrate the rich connections between CLL sites online. Unarguably, this tool works better in an interactive online context where the user can continue (infinitely) clicking into the various nodes to expand the map. Those reading this work online with Java installed on their machines can click on the URL to access the maps and continue the network mapping in order to make use of these important visual metaphors for enhancing the networking points I am making in this work. All readers can consider the part that technological software such as TouchGraph, Blogger, and SurveyMonkey, and the hardware that hosts them have played as essential non-human actors in making this a successful research network in its own right.

## **Translation: Launching the Project: Inviting Participation**

Aiming to trace the connections between narrative objects and actors representing CLL online, and to identify key versions and sub-texts of CLL in those networks, I initially decided to observe, record, and map new and archived material posted by members to the Macmillan CLL, SLL, and HCL community from my date of diagnosis over a three year period. These included personal narratives, research papers, medical education texts, videos, blogs, advice from official support agencies and campaigns, lab reports, and news reports. At this stage I also decided to chapterise the work according to key themes addressed in the field. These were broadly divisible into concerns with diagnosis; prognosis; treatment; and survival. The latter was later dropped as a discrete chapter from the PhD due to word count limitations, although many of

the issues inherent in survival narratives are addressed in the remaining chapters<sup>19</sup>, and it is my intention to publish the thesis as a book, including chapters on circulating narratives surrounding 'Survival' and 'Dying'. Some of the themes produce more activity in the networks than others. Over the course of this four-year project, huge advances have been made in the treatment of CLL. I also found myself undergoing treatment during the project when my disease took a sudden and unexpected aggressive turn in 2013/14. Consequently, the Treatment chapter is considerably longer than the other chapters. I made the deliberate decision not to attempt to organize the multiple associations of the longer chapters into perhaps neater, but potentially reductive sub-themes, as the diverse, open-ended chain of thematic associations reflects the real-world rhizomatic nature of the fields studied. Initially concerned that this may be daunting for readers, I came to (what I hope proved to be the correct) conclusion that the narrative structure created by the Translation/Perspective sections in each broadly themed chapter already provides natural breaks for the reader.

Permissions to launch the project on the site were obtained from the online community managers. Following Mann and Stewart's (2000) suggestion for a separate site outlining aims and objectives of the research project, I set up a blog where potential respondents could read about the project, ask questions, and download consent forms to agree to their postings being used in the research (see figure 7). The project was then launched in the community with links to the blog (see Appendix 2 for invitation to participate, and Appendix 3 for a screenshot and

<sup>19</sup> Further work on survival (and death) in the CLL networks will be undertaken beyond this project however in order to make maximum usage of the data collected in the remit of this ethnography.

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URL for the blog).



**Figure 7: JULESK (2013). “In Our Blood” Blog set up to inform participants and provide information and consent forms [Screenshot] 02/01/2013. Available at: <http://julesk-inourblood.blogspot.co.uk/> [Accessed 02/01/2013].**

Despite my best efforts to explain the project and reassure group members about confidentiality, I had anticipated some resistance to my dual status as member and researcher (Hudson and Bruckman, 2004). The initial trickle of responses were mainly positive, some requiring further information, and just one expressing concern that my dual status might threaten confidentiality and ability to post freely on the site. Another member insightfully interrogated my methodological approach:

You talk of studying the collective 'stories' of the contributors from this forum and how the experience shared and support and advice given assists and informs on living with the disease ... How will that be possible Jules if you don't get unanimous agreement to use 'stories and contributions? ... You will be aware that only a small percentage of

members actually contribute and there are indeed 'key players...who supply invaluable information and scientific updates (anonymous, private message Macmillan site 22.11.12).

Seeing this as an opportunity to articulate my methodology through interaction in the field, I responded in detail (see Appendix 4 for full response). The respondent in question was highly research-aware, and my response was pitched accordingly:

I'm not actually looking at dynamics/hierarchies/roles of individuals in the community - but at the way we are linking and *circulating* information, and translating it into our everyday experiences. I need some examples of that translation, but I don't need to look at *everyone's* contributions for this to work - it's not an ethnography of the community itself, but of the disease as it is broadly represented in the community (Kennedy, private message, *ibid*).

A reassuring absence of overt resistance was certainly overshadowed by a general lack of engagement at this stage. Initially exhilarated by finally going live with the project, this period was something of a 'reality check'. A number of obstacles appeared that made it seem as if my research project as network might actually fail at this point. Was my project interesting enough or relevant enough to the community? Were my aims and objectives articulated clearly enough? Was the group de-stabilized by my "coming out" as a researcher? I was forced to re-think some of my approaches. Primary among those was the issue of how to gain informed consent from my respondents without appearing bureaucratic or threatening community privacy. To comply with the vulnerable subject research guidelines set out by the ethics committee and outlined in the following section, respondents faced the onerous process of downloading, signing, and returning consent forms. Although several determined members

completed this process (or variants of it such as e-mailing me consent), others disengaged. At this moment the research project as network began to fall apart. The issue of consent needed approaching in a different way or my project (like Aramis) might turn to rust as translations stuttered due to an excess of passive intermediaries over active mediators. The following section reviews some of the contexts and inscriptions I engaged with as a researcher during the process of moving the project forward.

## **Perspectives: Ethics in Online Research**

The project aims demand close observation of the practices and postings of those engaged in selected CLL networks, and require informed use of participant postings, auto-ethnographic input, and broader observation of emerging traces and subtexts in the networks through digital fieldwork<sup>20</sup>. As virtual ethnography evolves into a distinct field exploring the cultures, practices and technologies that shape our everyday lives in a digital era, researchers encounter a new era of ethical challenges. These are particularly acute in online work with those considered 'vulnerable'. Whilst 'vulnerability' is an imposed assumption that may be challenged by those to

<sup>20</sup> In digital ethnography, the concept of 'fieldwork' is elastic, stretching traditional definitions to accommodate participant observation in a range of virtual contexts. Annette Markham (2012a) acknowledges that such radical adjustments to the activities of fieldwork are required in digital contexts that 'they hardly resemble fieldwork anymore', advocating scrutiny, problematizing, and systematizing of the 'messiness' of digital methods in order that innovation in the field is afforded visibility and validity. See Annette Markham for her pertinent blog post 'Deconstructing the Term Fieldwork' concerning the need to reconfigure the perception of "fieldwork" in digital research environments (Markham, 2012a)

whom it is applied, in research guidelines<sup>21</sup> it applies to subjects whose minority status, ill-health, age, or infirmity may leave them open to physical, emotional or psychological exploitation. Eliciting informed consent, protecting confidentiality and privacy, and considering the risks and benefits of a study in contexts of fairness are all considered particularly significant when working with groups who may be vulnerable (Flaskerud, J.H. and B.J. Winslow. 1998: pp 69-78)<sup>22</sup>.

As discussed, online health communications provide rich research data, some even claiming that more authentic narrative accounts can be found online than in formalized research settings (Suzuki and Beale, 2006; Grinyer, 2007). Others suggest that this provides opportunities for more ethical approaches to data collection than traditional face-to-face settings (Lewis, 2006; Nosek et al, 2002). Online ethics is not without its challenges however. Issues of privacy, informed consent, definitions of vulnerability, location, autonomy, representation and control play out in a highly contested arena of ethical decision making online for which very few definitive guidelines exist. Researchers are still picking their way across this ethical minefield, and each section of this chapter is set against that backdrop, addressing ethical issues as they arise in the methodological evolution of the project.

<sup>21</sup> See ESRC Framework for Research Ethics (2010), Updated September 2012.

<sup>22</sup> See Lancaster University's excellent resources for social science research ethics for further discussion of vulnerable groups and individuals in research contexts <http://www.lancs.ac.uk/researchethics/4-1-intro.html>

In terms of confidentiality, arguments persist around definitions of privacy and ownership of content posted online. Bruckman questions the relevance of the human participant model of ethical approaches to internet research altogether, espousing instead a kind of creative commons of online artefacts. There are caveats though, where password protection, website policy prohibition, or 'highly sensitive' material are concerned (Bruckman, cited in McGeehin Heilferty, 2010:950). Bassett and O'Riordan see the privacy constraints of the human subjects model as potentially *unethical* if applied routinely in internet settings, emphasizing instead a 'political imperative for visibility' through advocacy for those under-represented elsewhere (Bassett and O'Riordan, 2002: 243). Shani Orgad (2007) reflects this in relation to her work with online breast cancer support groups in her view that private communications can act to *limit* understanding of what it means to live with a particular disease.

Tensions clearly exist then between definitions of 'vulnerable subjects' and 'sensitive material' inscribed in the human subjects approach, and the political imperatives of an advocacy approach. For many closed group members, being advocated for by external (or even member) researchers may not take priority over a sense of trust and control over who shares their stories. Site is also an issue. The Association of Internet Researchers Ethics Working Committee (Markham et al., 2012) calls for attention to the location of the research, differentiating between blogs, listservs, chatrooms, semi-private communities and so on; the nature of the participants, and the potential risks and benefits of the research. In each of these locations, members' expectations of control over who is in their audience will differ.



Once a researcher has access to any respondent's narrative it is vulnerable to all kinds of translation. McGeehin Helferty (2010) identifies six key potential risk areas for those writing about illness online specifically:

(1) the potential for the creation of 'hero' stories; (2) the potential to interfere with the author's autonomy; (3) the multi-layered nature of 'vulnerability'; (4) lack of proprietary control over life event descriptions of serious illness published online; (5) the ambiguous nature of the participant and object of the research; and (6) the relative ease of access to the writing (McGeehin Helferty, 2010:951).

Annette Markham expands on the threat to autonomy implicated above in observing the potential to "alter the narratives merely by seeking informed consent to study them" (*ibid*), an anxiety expressed by one of my own respondents:

My only concern is that my utterances are very very un-earthshattering, and I worry that I will be aware of that when posting on the Mac site in the future and maybe (very unintentionally) change the way I respond (Macmillan Community Respondent 1, November, 2012).

Such insight into the potential pressure to 'perform' in postings lends weight to those seeking a more nuanced view of the role of performativity more generally in the interpretation of illness narratives (Atkinson, 2010). Other scholars bring serious consideration to issues of *representation* in illness narrative research, particularly surrounding the interpretation of metaphor in illness narratives (Frank, 2008; Sontag, 1991). McGeehin Helferty suggests that clinicians and researchers address such challenges by positioning themselves *with* respondents, rather than acting as a spokesperson *for* them. To do so demands sensitivity in political

advocacy approaches, and this chapter will address that in relation to my own role as a politicized member-researcher in due course. Next though, I focus on my failing project network and how I overcame the ethical obstacle of gaining consent to keep it alive.

## **Translation: From Hub to Nodes with Consent**

Around this time CLLSA UK<sup>23</sup> launched a new site hosted on HealthUnlocked, a community network site that currently boasts around 70,000 members, sharing more than 800,000 health experiences according to its website<sup>24</sup>. Membership uptake on the site grew rapidly in the first few weeks, with a global mix. Although a significant element of cross-membership can be traced between the CLLSA site on HealthUnlocked and Macmillan sites, the virtual architecture of the former seemed to lend itself more intuitively to a research based exploration. The inclusion of polls, blogs, and direct questions into the design of the site itself offers a range of discursive possibilities for discussing CLL, underpinned by the spirit of inquiry that characterizes the HealthUnlocked ethos (see Figure 8). The site has gone from strength to strength with constantly growing membership, and is a successful network held together by key actors, some

<sup>23</sup> The CLLSA UK is a registered UK charity with a membership of around 900 set up in 2005 by a group of four CLL patients (Robert Cork, Chonette Taylor, Howard Pearce and Sue Waldie) who initially made contact over the internet. The main aim of CLLSA is to provide help and support for patients with CLL (and similar related conditions) and their carers. (CLLSA UK 2014a)

<sup>24</sup> The site hosts over 170 condition and wellness communities from established organisations such as the CLLSA UK. The CLLSA site invites members to write and respond to blogs, to ask questions and seek advice from the rest of the community on a range of issues experienced by those living with the disease, and to post and respond to short polls about those experiences (Health Unlocked, 2014).

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of who feature large in the coming chapters.

Image removed due to copyright restrictions

**Figure 8: HEALTHUNLOCKED CLLSA (2013). Member Homepage [Screenshot]. [Online] 21/01/2013. Available at: [cclsupport.healthunlocked.com](http://cclsupport.healthunlocked.com) [Accessed 21/01/2013].**

Aside from the obstacle of gaining written consent, it was also becoming clear that focusing on the Macmillan site alone was overly restrictive. This highlights a need for researchers to acknowledge a high degree of flux and evolution in online support communities as field.

Memberships change, old sites might fail or weaken as networks as new sites emerge, and people “drift” between nodes. Useful research could be carried out using the methodological design I experiment with here to explore exactly *why* some networks weaken and others grow stronger, but that is not the prime focus of this iteration of my research.

Shifting the focus on the Macmillan site from my central “hub” to just one “node” in a broader network of CLL communication online, I expanded the range of the project’s aims for a dynamic multi-sited ethnography of CLL online. If single sites as points of convergence are too restrictive, and people move constantly between nodes, then it made sense to follow Marcus (1998) when he says that creative ethnographers need to “follow the story, follow the people, follow the metaphors” (cited in Markham, 2013). I also wished to follow metonymic chains of association and likeness. I would follow the narratives of CLL across the networks, identifying key nodes, connections, actors and themes. To target as many of these as possible, I needed to launch my project into several of the key global communities – not just one.

Starting with HealthUnlocked, and drawing on my experience of launching the project on the Mac site, participation was invited from the 160 plus<sup>25</sup> membership through the site’s private messaging facility. The invitation was re-written in response to a perceived lack of clarity in the first iteration launched on Macmillan (see Appendix 5 for the revised version). Launched on 29<sup>th</sup> December, 2012, I received around 20 responses from people willing to participate over the following days.

Two key obstacles persisted, and my responses to them changed the shape and impact of the project as network significantly. Firstly, gaining informed consent online continued to present

<sup>25</sup> Membership figures on the site recorded as 1700 plus in January, 2015 (CLLSA UK, 2015).

challenges<sup>26</sup>. Eventually, all information from the consent form approved by the ethics committee was transferred to a secure, encrypted online consent form hosted via online survey company SurveyMonkey (see Appendix 6 for a sample consent form), and all respondents were messaged with information and links to the online form. I perceived this approach to be more accessible, less laborious, and offering a higher degree of confidentiality. Respondents were wholly positive, one in particular expressing relief:

Well done! I wondered whether to respond earlier about how your requirement to print, sign, scan and email the consent statement was quite likely a major factor behind your limited responses and I see you've successfully overcome that (AussieNeil 3 Jan 2013).

Secondly, several people replied stating that they were keen to actively participate, but that they would rather contribute their experiences directly to me via e-mail in response to questions, rather than consent for me to use their online postings. As a group member myself, I understood this desire to retain control over contributions, and maintain autonomy, freedom of expression and confidentiality of their community online postings (McGeehan Heilferty, 2010; Markham, 2008). On the strength of this feedback, I designed a questionnaire, described in detail in the next section.

<sup>26</sup> Respondents were asked to consent by copying and pasting a statement from the invitation into their response message, obviating a need for hard copy consent forms, but problems persisted with a lack of consistency in responses to this request.

Including the CLLSA Health Unlocked site, and opening up online consent forms and questionnaire had the unexpected result of attracting global attention as networked CLL patients around the world became aware of the project and actively sought inclusion. Within weeks the project had been launched on the ACOR list, through Facebook CLL support site Bad to the Bone, and through dedicated support site CLL Canada. Several high-profile CLL bloggers and advocates also expressed interest and consented to my use of their postings (see Appendix 7 for a selection of support messages). Obstacles removed, nodes added, networks opened up, and this PhD project turned in a matter of weeks from a failing research object to a vibrant network actor in its own right.

### **Translation: Accommodating Respondent Needs for Privacy (A Survey is Born)**

The need for a more specific, direct form of eliciting information to enable those who didn't want their postings used as data was a significant issue that I hadn't considered in my original project design. My original vision had been one of mapping respondent postings to selected sites in their 'natural' day to day practices, and around 50 respondents consented to this making my aims viable. However, the fact that many more people *didn't* want to participate in this way whilst expressing very real desires to be part of the project led me to reconsider. Not wishing to exclude willing participants to the project by imposing a rigid methodological approach to data collection led to the introduction of an online survey also using

SurveyMonkey, and launched in the same e-mail as the consent form.

## **Asking the Right Questions**

The survey allowed for some focused questions surrounding the online practices of respondents in relation to their disease. This was an unexpected bonus of the questionnaire element as it allows for incorporation of respondents who don't post regularly online.

Functioning as a mediator, the questionnaire both extended the range of data collection and created visibility in the network for some previously unseen actors<sup>27</sup>. The first eight multiple choice questions elicit data on online practices through interrogating sites used; levels and types of participation; and whether internet use translates to effective coping strategies and clinical relationships. This allowed for identification of key nodes and actors in CLL online, and how online narratives might produce effects for managing the disease in everyday life.

Questions 8-14 are open questions, inviting comment on the key themes of living with CLL already identified through fieldwork. This was largely a case of identifying the major concerns for discussion surrounding experiences of CLL online, and following narrative chains of associations to some of the broader social, cultural, and scientific contexts relevant to each. A condensed list is provided here as a framework for question 8 through to 14:

<sup>27</sup> In this way, the research tool itself becomes an actor - literally a 'body' of research, a concept that can be more broadly extrapolated to the status of the research project as a whole as a 'network' in its own right.

- Dealing with diagnosis
- Understanding and coming to terms with prognosis
- New treatments and expectations for the future
- Learning to live with CLL
- Impact of chronic leukaemia on perceptions of time
- Impact of disease on relationships

Each question asks the respondent to write as much or as little as they like about the issue, and to identify if and how they have used the internet to help negotiate it. Question 15 seeks comments on any areas the respondent feels I may have overlooked, allowing for identification of any versions or sub-texts of CLL not already recognized through fieldwork. Responses from these key themes were eventually organized under the streamlined chapter headings of this work as Diagnosis, Prognosis, and Treatment, with a dedicated CLL Online chapter to outline the practices of CLL activity online and its contexts.

Dhiraj Murthy (2008) extols the virtues of online questionnaires as an element of digital ethnography, citing ready access to large data sets without the need for transcription, and the relative ease of implementing a range of structured responses, adaptive questions, and point-and-click responses (Murthy, 2008: 842). Gunter et al. (2002: 233) have also observed a tendency towards speedier and higher rate of return than with traditional survey methods, and 'richer' responses to open-ended questions (*ibid*). The survey collection closed early in 2014



with 260 people starting the survey and a completion rate of 184 (72.7%) (See Appendix 8 for sample copies of the completed survey).

## **Translation: Managing and Analysing the Data**

Through daily fieldwork, I was able to identify and selected the key narrative flows that form the Translation sections in this work. Blog excerpts, conversational threads, research papers, news reports, institutional documents and so on were observed daily over a four year period according to narrative type and source, the particular enactments of CLL they speak for, emergent themes, and intersections with other textual actors in the network. The Translations in this work were selected as particularly relevant examples of the multiple narrative actors and enactments I encountered, and their various intersections. The criteria was to include as many enactments and translations as possible to demonstrate the multiple ontologies of CLL online, and to demonstrate network effects between enactments where possible.

As far as data from the questionnaire is concerned, SurveyMonkey's built-in analytical software enables downloading of responses as completed individual questionnaires, or by numbered question, allowing for individual case studies as well as drawing out universal narrative themes or sub-texts. The closed questions have contributed quantitative secondary data revealing the major networks, and some qualitative assessment of online practices.

Having inflected the questions toward the key themes of narrative interest already identified obviated the necessity for coding data from scratch, and allowing for data alignment with fieldwork, although data analysis remained alive to emergent possibilities not already noted. The survey produced a fascinating overview of internet use among CLL patients, identifying key nodes in the network, key actors, patterns of online behavior, key themes of concern for CLL patients, and over 100,000 words of open-text responses from CLL patients globally. As such, it became a central pillar of data collection for this work, and represents one of the major CLL specific research projects of patient behaviours and opinions undertaken to date. The themed findings and analysis chapters are preceded by a chapter dedicated to mapping the survey responses specifically, and individual responses are threaded through all sections in an attempt to layer their voices with the multiple other textual objects making up each themed section. One of those textual objects is my own story, and the following perspective section explores some of the methodological contexts for that.

### **Perspectives: Autopathography as Auto-Ethnography**

As the story of this project so far has revealed, my own experience of disease is central to the imperatives for, and politics of my research. However, my methodological approach acknowledges that my particular narrative object of CLL is mutable, and that I am just one amongst a range of actors whose stories circulate online. This section will address contexts for accommodating my own story into the ontological politics of my research design, starting with

some of the literature on illness narratives as a form of identity re-construction.

The task of transition to “becoming” seriously ill is a process of adjustment to the changes imposed on lifestyle or identity by a diagnosis of illness enacted through the body<sup>28</sup>. The pre-diagnosis notion of *self* or *selves* is challenged by both the ‘othering’ effects of the language of illness, and changes imposed on the body by physical symptoms. The sick move through the world in bodies foregrounded by their failings, flaws, and fault-lines, in which time and being are circumscribed by the knowledge and practices necessary to manage the impact of the compromised body on daily routines. Such embodied change, it is suggested, must be accommodated somehow into an ongoing “‘story’ about the self” (Giddens 1991: 54). Easy assumptions behind assertions that everyone has a need to re-write selves and identities in ill-health are contestable as will be seen later in this work, but as the literature reveals, contemporary society offers a number of generic ‘templates’ for illness narratives (innocent victim, deserving victim, warrior, restitution, passive recipient, stoic to name a few) which are variously taken up, problematised, or rejected outright by those writing about their own or others’ experiences. A growing field of practice in offline and online contexts, autobiographical narratives of illness or disability constitute a generic form of literature in their own right, one that G. Thomas Couser refers to as ‘autopathography’ (Couser, 1997: 5). Autopathography that relates personal experience of illness to broader cultural questions is in a sense a form of auto-

<sup>28</sup> See David Morris’s (2008) work on Diabetes, Chronic Illness and the Bodily Roots of Ecstatic Temporality for an in-depth consideration of phenomenological understanding of chronic illness in relation to time and the body. In this paper, Morris draws on Merleau-Ponty’s *Phenomenology of Perception* (1962), and Heidegger’s *Being and Time* (1962) to explore implications for self-management of chronic illness.

ethnography - a methodology for exploring what it means to live with disease for those who are actively engaged in doing so. As illness progresses, so one enters new territories that invite translation, almost as a travel writer where the encountered inhabitants of the 'discovered' world are circulating actors (subjects and objects) – online in my case. Translations are less semiotic or sign-based (although, as the reader can see, I discovered many diagrammatic representations in my journeys) than affective, sense- and bodily-based. The encounters with new territories and the translations necessary for understanding, despite their - often virtual – (de)natures, are necessarily felt in the body as 'foreign bodies' (Lingis, 1994).

As someone actively engaged in living with disease, I have found autopathography to be a useful method for exploring what that means for me. I have practiced it in personal writing about my experiences, some of which remains private, but much of which has been posted in support communities, or written into this project. But what place can autoethnography occupy in a multi-sited ethnography? Being a participant observer living with the disease I am researching leaves me queasy when encountering the work of 'healthy' researchers seeking to externally impose forms of narrative coherence on the stories of their 'sick' respondents. This can be read as a research network effect in itself – a particular enactment of illness narratives that produces the results it is looking for rather than uncovering them as a truth that is waiting to be found<sup>29</sup>. Resisting a tendency towards positivist claims of universal truths underpinning

<sup>29</sup>Mike Bury (2010) wonders in relation to his earlier work on biographical disruption whether concepts of narrative construction, and re-construction in illness are merely artefacts of the research process itself that can't really lay any valid claim to the 'realities' of individual experiences (see Reeve et al, 2001: 210 for further discussion on Bury's insightful re-visiting of his earlier conclusions).

dominant methods, postmodern ethnographic method challenges the realist conventions and objective observer position of standard ethnography. Similarly, postmodern autobiography calls into question the notion of a coherent, individual self (Reed-Danahay, 1997:2). Identities are characteristically seen in such work as constructed and multiple, 'subject to' rather than 'subjects', and in contemporary feminisms, often in subjection. For pathographies, selves may be abject too (Kristeva, 1982).

Synthesizing ethnography and autobiography, autoethnography emerged as a response to the 'crisis of representation' in dominant positivist methodologies. In an approach to research and writing that seeks to "describe and systematically analyse (graphy) personal experiences (auto) in order to understand cultural experiences (ethno)" (Struthers, 2012: 23) the methodological outcome of auto-ethnography is at once 'process and product' (Ellis et al., 2011:1). This is evident in my own project that incorporates my unfolding experience of living with disease and the resulting relationships formed with other actants (process) into the research artefact itself (product). However, I remain alive at all times to the fact that my presence as one actor in a multiplicity is no *guarantee* that I will keep my interpretive hands off the others. Resisting that can only ever be a constant work in progress if we accept that "the self is porous, leaking to the other without due ethical consideration" (Tolich, 2010:1607).

Autoethnographic method is in itself a contested practice. Some see it as the goal of reflexive ethnography to "fully acknowledge and utilize subjective experience as an intrinsic part of

research”<sup>30</sup> (Davies, 1999: 5). Visibly incorporating subjective experience into ethnographic work can be interpreted disparagingly as “author saturated texts” (Geertz, 1988) ceding sociological relevance to self-absorption. In response, Leon Anderson suggests synthesizing evocative, deeply personal ethnography with more traditional ethnographic practices, listing key features of a model for ‘analytic autoethnography’:

(1) complete member researcher (CMR) status, (2) analytic reflexivity, (3) narrative visibility of the researcher’s self, (4) dialogue with informants beyond the self, and (5) commitment to theoretical analysis (Anderson, 2006: 374).

Although I make no claim to pure ‘analytic autoethnography’ in this project, I could certainly satisfy all five criteria at face value<sup>31</sup>, although notions of membership are complicated in multi-sited ethnographies where a researcher can be a member of a larger, more diffuse network without being a bona fide member of some of the more local nodes in the network. However, there is a sense in Anderson’s methodological aspirations of research driven to a particular endpoint, rather than an exploration in its own right as privileged by those narrative approaches that resist abstraction and explanation. Phenomenological experiential accounts are regarded by the latter as wild, unruly, and rebellious forms of inquiry, locating ‘ethnography as a journey’ as opposed to a teleological ‘destination’ (Ellis and Bochner, 2006: 431).

<sup>30</sup> Poststructuralist feminists such as Hélène Cixous (Cixous,1981) problematize such ‘felt self’ experience where the ‘feminine’ self may best be expressed as an impression of expressed breast milk, as a gesture of succour, and as an ‘invisible ink’ that is the trace of ‘mother’s milk’. The subjective experience may then never be gathered in as capital, as is common in a patriarchal model, but is constantly expressed as succour, as (m)othering.

<sup>31</sup> although arguably the notion of ‘complete membership’ requires interrogation, as no two individuals are likely to share all characteristics comprising their membership (Buzard, 2003)

Denzin's view of autoethnography as exceeding subjective account in its attempt to "reflexively map multiple discourses that occur in a given social space" (Denzin, 1997, cited in Spry, 2007:727) reflects my desire to map, not analyse, my presence as one actor amongst the multiple actors populating my research. It acknowledges the fluid subjectivities, multiple identities, shifting cultural boundaries and axes of power contingent on notions of self and society in late modernity. The following very brief Translation section incorporates exchanges between me and the ethics committee surrounding their initial concerns about my autoethnographic presence in the work. It demonstrates once again a moment where the inscriptions and traditional practices of enacting research presented as a temporary obstacle to my progress, and how I engaged with those inscriptions to produce network effects enabling the work to progress.

### **Translations: The Ethics of Autoethnography**

I have already acknowledged that being a participant observer doesn't preclude me from a potential, however unintended, to position myself at the top of a hierarchy of actors, nor does it exclude me from the power dynamics of my parallel position as a university lecturer and academic. Despite these challenges, commitment to visibility for multiple actors involved in CLL online, including myself as an individual with privileged access to the networks, is a significant factor in achieving my research aims.

When my proposal went to the RNUAL Ethics Committee in 2012, the response made a number of observations, prime among them being the suggestion that “the applicant should consider the effects of disclosing her own circumstances on this matter” (RNUAL Ethics committee response, 2012). Implicit here is the notion that my declared status as a CLL patient might actually prove coercive in its own right. The following excerpt is taken from my response (see Appendix 9 for full transcript):

...my own status as a person with CLL cannot be concealed within the current project design ... The spirit of this research as a collaborative endeavour within an already established group of which I am an active member is fundamental to achieving my aims...(Kennedy,2012).

In the context of continuing reflexivity surrounding my dual role as member/researcher, strong emphasis is placed on the importance of my status as a “native researcher” (Ellis, 2004; Denzin and Lincoln, 2008). I could not see a way that I could progress the work without disclosing my status as a CLL patient, not least as I would have had real trouble gaining membership to the groups set up for CLL patients and carers in the first place, apart from the factor of the dishonesty I perceived to be inherent in concealing such a significant fact.

In crafting a method that assembles the nuanced mapping of material relations through ANT alongside the raw auto/biography of material reality, I hope to create productive sites for political work at points where the two methods both converge and clash. Autopathography is an important political position here, but rather than trying to read all of the actors through the lens of my own experience, I want to flip the point of view so that my own narrative becomes



just one of the textual actors in field of multiple enactments. In network terms my presence can be seen variously as actor, network, and mediator, depending on my role at various stages and sites and of the work, and I constructed a detailed response to the committee's concerns based on my methodological position as Appendix 9 demonstrates.

After at their next meeting, the committee responded in full on 13<sup>th</sup> July, 2012, informing me that my work was cleared to proceed, that they were impressed with my defence of a fully disclosed auto-ethnographic position in the work, and suggesting that "the applicant incorporates a full ethics section into her PhD or produces a journal article on this topic, as her discussion and resolutions seem to advance the field rather than merely comply with it" (Extract from the minutes of the Research Ethics Sub-Committee's consideration of revised research ethics application submitted in response to the Committee's comments made at their meeting on 21st February 2012 (see Appendix 10 for a full transcript).

The project was back online, and the following Perspective section outlines briefly the evolution of the methodological field of ANT into current ontological approaches informing my design decisions to position my disclosed autoethnographic role as one of the multiple objects I want to work with.

## **Perspectives: ANT and the Ontological Turn**

Disease itself can be read as a concatenation of technological and human knowledge and practices produced and held together by multiple narratives. Diseases as entities are at once scientific, social, political, and fundamentally corporeal. The narrative semiotics on which ANT are based allow for bringing together bodies, texts and hardware to explore how together in networks they produce the practices and inscriptions on which knowledge and experience of disease is based. ANT provides a method for fine-grained readings of what passes between the social and the technical in the production of technological knowledge and behaviour<sup>32</sup>. Hybrid networks of humans and non-humans acting on equal footing produce techno-scientific knowledge, disavowing bifurcations such as natural/technical, human/non-human and focusing instead on the network transformations and translations that produce technological knowledge and practices. Some scholars have read techno-cultures themselves in this way (Plant 1997; Haraway 1997, Bassett, 2007). This approach is not without its critics. ANT (1990) has been criticized for being overly concerned with the 'how' of network associations in its attempts to show the embedded-ness of technology in keeping human relations hanging together, thus effacing the 'who' or the 'what' (Couldry, 2004). Through mapping sites in which political questions might be posed, rather than attempting to answer pre-determined questions through the mapping itself, some critics see ANT as copping out with an "I map, you decide; my map is

<sup>32</sup> In ANT the important work of peeling back and pinning out the layers of multiplicity, consensus, tension, and fragility that form the solid objects of institutions and knowledge is assumed to be more effective in catalyzing progressive awareness and potential change, than the process of suturing them together with existing social theory.

neutral” approach (Saldhana, 2003: 426). Saldhana wonders whether the ‘politics’ of simply revealing the material messiness of phenomena doesn’t ultimately serve to “put the researcher outside the field, just like in positivism”<sup>33</sup> (Saldhana, 2003: 426).

I can certainly engage with these criticisms as a researcher with a fundamentally personal-political investment in my work. 1990 ANT<sup>34</sup> is a little too bound in its rigid terminology, and just a little too flat in its ontological approach for me to work with comfortably. I tried, but it was with the post-1990 work of the ‘ontological’ turn that I felt most at home, where I felt that I could attend to matters of concern that I and others engaged in CLL networks as human actors rub up against every day.

Digital illness narratives often present as storied assemblages of the human and non-human objects that make up the disease experience. They become complex accounts of the way such networks of objects produce material effects on individuals and at the same time they operate as circulating objects in disease networks online with the potential to transform and translate knowledge in their own right. This work has so far acknowledged the role of technological, institutional and professional practices inherent in multiple enactments of CLL, and seeks to make them visible in the coming chapters. Those multiple enactments include patients’ autopathographic accounts articulating what happens when the technologies of disease

<sup>33</sup> Again, for a fuller For a fuller explanation see A. Saldhana’s deconstruction of some of Law and Mol’s work in his (2003) Essay ‘Actor-Network Theory and Critical Sociology’.

<sup>34</sup> For an overview of the evolution of ANT, including a definition of the term ANT 1990, see Sanna Rimpilainen’s, useful (2009) paper, ‘Multiple Enactments?’

intersect with or produce material human responses such as fear, grief, loss, pain, hope, relief, isolation and confusion. The ANT insistence on absolute symmetry between human and non-human actors can elide network effects and practices in the shadow of its dominant quest to identify the *immutable mobile* objects of scientific knowledge<sup>35</sup>.

The ontological turn, led by Mol (2002), and Law and Singleton (2004), locates objects as potentially *mutable*, and mobile, yet still hanging together. The complex glossary of ANT is superseded by new metaphors implying flux, and the ability for objects to travel across networks in different ways, and in multiple enactments. Fire objects (Law and Singleton), multiple objects (Mol), or fractal realities (Watson, 2010) characterize evolutions of ANT that seek to configure new forms of object relations. Law and Singleton, for example, distinguish between ‘fluid objects’ that change relatively gently and ‘fire objects’ that are more unstable in the sense that they show radical discontinuities. This evolution of conceptual mapping of objects states is important as it allows ANT to evolve approaches beyond earlier criticisms, yet acknowledge that current social science methods are poor at dealing with a number of facets of social life – for example:

<sup>35</sup> Very basically speaking – immutable mobile objects are inscriptions that remain consistently anchored into the centre as they cross borders, and combine with other objects. Jones (2005) uses the example of a map which is “mobile while the actual land is not. It is immutable while a native man’s drawing on the sand is not. So by drawing a map on paper, you bring the remote land back to the center while you are not really taking the actual land with you” (Jones, 2005:16). This notion is often used in the case of scientific imagery, but nuanced by Kaiser (*ibid*) who argues that such imagery (diagrams, graphs, photos and so on) demonstrate a ‘plasticity as they circulate across different research territories. For a full explanation of Immutable mobiles in scientific research see Professor David Jones’s (2005) paper In Conversation with Bruno Latour: Historiography of “Science in Action”.

- The distributed (that is to be found here and there but not in between, or that which slips and slides between one place and another).
- The multiple (that which takes different shapes in different places, with the non-causal, the chaotic, the complex).
- The sensory (that which is subject to vision, sound, taste, smell).
- The emotional (time-space compressed outbursts of anger, pain, rage, pleasure, desire, or the spiritual).
- The kinaesthetic (pleasures and pains that follow the movement and displacement of people, objects, information and ideas).  
(Law and Urry 2004, cited in Watson No date: 37).

To think of CLL as a unified category, or a singular pathology, is misguided. CLL is a heterogeneous disease with applications to all of the above phenomena. It is distributed in that it slips and slides between varying enactments; multiple, in that it takes different shapes both within its own textbook inscriptions, and within the various practices that shape it; sensory, particularly in relation to its invisibility; profoundly emotional for those living with it; and kinaesthetic, in the often ongoing painful displacement of CLL patients from biographical frameworks and social worlds.

Latour himself has recently drawn attention to what he describes as the 'exhausting' limitations of contemporary critique which he now sees as somehow failing in its approach (and here he includes his own work) to adequately account for 'experiences, beliefs and passions – engaged with but not reducible to the facts of material life' (cited in Jurecic, 2012:16). Latour acknowledges his own mortality in the reference to colon cancer tucked away in an eclectic list of experiences unaccountable for simply by fact (or fetish):

I am, I have always been, when I know, for instance, that the God to whom I pray, the works of art I cherish, the colon cancer I have been fighting, the piece of law I am studying, the desire I feel, indeed the very book I am writing could in no way be accounted for by fetish or fact, nor by any combination of those two absurd positions (Latour, cited in Jurecic, 2012:16).

Latour calls for scholars to “approach matters of concern with tools whose purpose is not to “debunk” but to “assemble” (*ibid*). Paying attention to matters of concern, assembling them as and in relation to other objects doesn’t expunge the things that matter to humans from network studies. Mapping the intersections, translations, clashes, tensions, or interferences between multiple online narrative enactments in terms of the ‘who’, and ‘the what’, reveals something of the ontological politics of disease. Who shouts loudest when clashes occur, and – importantly - about what? Patient advocates and access to drug trials for example.

Patient/physician blogs exposing the tensions between clinical and patient enactments of CLL that underpin frustrations in clinical relationships in an attempt to improve them might be another example. Further, there are the everyday network effects of digital platform use for mutual sharing of personal enactments of CLL through stories in support communities, and so on.

Understanding how objects hang together in multiple sites is still an important aim. That the often disparate enactments of a disease still coalesce under a single name is testament to the work required to avoid total fragmentation. The multiple body acted out or on in practice still hangs together in the hospital field as the object of a single disease. A disease enacted, Mol tells us, is “more than one – but less than many” (Mol, 2002:55). Does that, I wonder, translate

to multiple narrative enactments of a disease online, which archives and circulates inscriptions from newspaper articles and lab reports, through policy documents and research papers, to pharma stocks and shares, family photos and memorial sites? To test this out is a big task, but CLL online is distributed across all of these narrative forms at key sites. By observing the topography and activity, I can think about 'how' CLL networks are formed online. By observing 'who' it is that circulates them, I can identify key actors in the CLL 'networks' online. By observing the concerns of the circulating narratives, I can reveal 'what' is important to people with CLL. By observing the intersections, translations, and interferences, I can explore the potential for circulating CLL narrative objects to exert material effects on each other and actors that produce and consume them. Such nuanced data collection presents challenges in writing up the complex assemblages of information orchestrated in this project. In short, as I travel more deeply into the territory of CLL I appreciate a complex set of landscapes that I inhabit as a multiplicity of symptoms and not as a coherent illness or disease. This, in turn means that ethnographic work carried out in these multiple landscapes must offer multiple translations, dialogues and polyvocality. As a fundamental element of the project design, these issues will be addressed in the following Translation section.

### **Translation: Writing the Network through Textual Layering**

I am by no means the first academic to write my disease-as-research. In *Teratologies* (1997), Jackie Stacey combines autobiographical narrative with a cultural study of cancer. Stacey organises the cultural, the personal, and the methodological through text and image in themed

chapters in this touching and powerful assay of living with cancer. Her political stance (feminist) is clearly articulated in her work, foregrounded as critical analysis, and illustrated through autobiographical experience. Implicit in work such as Stacey's is the fact that selves are always located in relation to the *things* that make up the world, the technologies, institutions, ideologies and systems within and through which human selves operate.

Already referenced, AnneMarie Mol's (2007) ethnography of atherosclerosis, *The Body Multiple* lays bare the relationship of a disease to the texts and technologies that define it through an ontological philosophy drawing on earlier incarnations of ANT. Through careful layering of field observations and relevant literature in the presentation of her work, Mol writes through the politics of her method, resisting analysis and abstraction. Instead, she brings together empirical observation from her fieldwork that accommodates text and images as a continuous discrete text running along the top of the pages in the book. Underneath them, like a continuous, detailed footnote to the entire text, runs a separate reflexive literature review and methodology. The two cannot be merged and read as one text. The reader is required to find a way to read them separately yet still to relate them one to the other. In structuring her work in this way, Mol makes the point that these are simply two different enactments of research. Marrying the theoretical to the empirical in a seamless text constructs a new reality in which all that happens in the clinic and to the patients is *subjected* to the analytic frames, abstracted to them and explained away by them. Such analytic coherence is easier to read, and to write, yet it is arguably too tidy, too insistent, too conclusive to accommodate multiplicities both of the



research objects and of the research as an object in itself.

In his story of *Aramis* (1996), Bruno Latour assembles multiple practices, documents, and interviews in a non-hierarchical account of the planned high-speed transportation system for Paris's ultimate failure to get off the ground. In structuring the narrative as an assemblage, Latour positions the reader as an actor network theorist. Poet Tan Lin's 2012 work *Heath Course Pak*<sup>36</sup>, a 'novelistic' exploration of online responses to actor Heath Ledger's death in 2008, positions his readers similarly with a focus on the poetics of writing the social:

As a test case, the writing explores Actor-Network-Theory, considering Heath both as an actor-network in ANT terms and a coterminous mode of sociological accounting...What Lin's poetics specifically shares with ANT is an emphasis on demystifying through detailed description, tactical citation, assemblage, and deployment through mediators and their relations, where every actor is a network...These 'born-digital' actors include intellectual property disclaimers, popular advertisements, autobiographical details, ticket stubs, rejected articles, celebrity blogs, and RSS feeds (Snelson, 2010).

Tan Lin brackets very little in his literary accounting of Ledger's fans' engagement online and off with reports of his death, from the copyright of the RSS feed logo, links to online bookstores for books underpinning his method, autobiographical detail of the fans own lives, and the packaging of the takeaway coffee they consume whilst online, he stretches out the detail into a

<sup>36</sup> See also Lin's earlier work, *Heath (plagiarism/outsourcing), notes towards the definition of culture, untitled heath ledger project, a history of the search engine, disco OS* (2009) – a montage of cut and paste online data described by Danny Snelson (2010) as a test case, in which the writing “explores Actor-Network-Theory, considering Heath both as an actor-network in ANT terms and a coterminous mode of sociological accounting...What Lin's poetics specifically shares with ANT is an emphasis on demystifying through detailed description, tactical citation, assemblage, and deployment through mediators and their relations, where every actor is a network....” (Snelson, 2010: no page).

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nano-narrative of daily life focused on responses to the death of an individual among online fans (see figure 9).

Image removed due to copyright restrictions

**Figure 9: Figure 9: LIN, TAN (2009) Excerpt from Plagiarism/outsource: notes towards the definition of culture : untitled Heath Ledger project : a history of the search engine : disco OS [Scan]. Tenerife: Zasterle.**

Inspired by the narrative approaches of Latour and Lin, my aim is that 'In our blood' will function similarly as actor network and sociological account. I have created a narrative structure that draws on the layered presentation of Mol, and Stacey's organization of critical materials under emergent sub-texts read through biographical experience. Each themed chapter reflects the key issues addressed in the nodes and networks observed through

ethnographic fieldwork. The work is structured in a format that layers relevant contextual or theoretical 'perspectives' with examples, or 'translations' of circulating narratives presenting multiple enactments of CLL online. In the Translation sections there is a focus on the range of narrative forms, sources and intersections allowing for mapping of key actors, nodes and mediators. Screenshots and images from relevant texts and online platforms are interspersed throughout to convey a visual sense of network nodes and inscriptions. These might include (but not exhaustively):

- Personal narratives from community members.
- Research papers.
- News features.
- Lab reports.
- TouchGraph/SurveyMonkey visual data.
- Medical Drs.' letters.
- Medical Imaging.
- Blog postings.
- Screenshots and quotes from videos.
- Relevant methodological and theoretical literature.
- My own autopathographic narrative.

In its interpretive role, the writing up element of the research process is a profoundly political one, and as we begin to explore evolving narrative cultures through evolving methodological

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frames, it seems more pertinent than ever to remember that “the more human inquiry becomes qualitative, the more it needs to ask what is required of writing and of language” (Van Manen, 2002).

The narrative approach of this work sets out to demonstrate a number of key issues, for example: What discursive, institutional, and individual narrative enactments of CLL can be traced, across the nodes and networks identified; what knowledge, practices and changes (acts of resistance/evolutions/becomings) might be produced where they intersect; who (or what) drives the flow of these narratives around the CLL networks online; and what might we learn from them? The Translations and Perspectives of the following chapters aim to address these issues under their respective themes.

## **Chapter 2: CLL Online**

### **Introduction**

As suggested in the introduction, CLL patients have a particularly active online presence. The chronic progressive nature of the disease gives people time to research their condition and establish and maintain online support connections. Although findings from the Pew Report 'Chronic Disease and the Internet' (2010) indicated that people living with a chronic disease are less likely to have regular internet access due to a number of external factors (including the older age range of this group), it concluded that, once online, their disease management was likely to be significantly influenced. 'They unearth nuggets of information. They blog, they participate in online discussions. And they just keep going.' (Fox and Purcell, 2010:4). This overall view is supported by internet use amongst CLL patients, and this chapter sets out to nuance that through mapping of online CLL networks, and exploration of individual behavior through responses to the online survey forming part of the fieldwork in this ethnography, and outlined in the Methodology chapter.

The chapter outlines who was active online, what sites they felt were most useful, if and what they posted themselves, why they might choose not to post, whether engaging with CLL communities online helped them to live with their CLL, and whether it had any impact on their clinical relationships with their doctors. As such it does some of the work of identifying key actors, networks and nodes, and prefaces the thematic chapters that follow.

## **Perspectives: From Sick-Notes to E-patients**

Dominant perspectives in medical sociology can be broadly categorized as functionalism, political economic, and social constructionism (Lupton 2012). Traditional functionalist approaches stress the physician's social function in legitimizing the 'sick-role' (Talcott Parsons, 1987). Political economists instead focus on medical professionals as major agents of social control in late modernity, complicit in coding contemporary health care in ways which both elide the underlying causes, and continue to commodify health care itself as a narrow range of biomedical products<sup>37</sup> (Illich, 1976; Zola, 1981; Epstein, 1990; Russell and Schofield, 1986). This economically determinist model has largely been superseded by the kind of social constructionism that precedes the methodological approaches I have drawn on for this work. For example, Michel Foucault (1973) reconfigures 'the medical gaze' as diffuse micro-systems of power producing knowledge and subjectivities that can be both repressive *and* productive. Institutional surveillance is taken up by individuals in practices of self-surveillance in response to various discursive regimes.

Foucault has been criticized for his view of patients passively submitting their bodies to medical power and surveillance, aligning himself in later years with fellow French post-modernists Gilles Deleuze and Felix Guattari, whose 'body-without-organs' metaphor symbolizes resistance to dominant external powers (bio-medicine in this case) through constant re-definition and re-

<sup>37</sup> Such approaches have been criticised as unrealistically radical and unreasonably nihilistic in its view of an oppressive dichotomy in the doctor patient relationship (Lupton, 2012: pp6-7),

territorialization by alternative discourses. Here, the striated space of medicine with its traditional, historically-contingent hierarchies is re-territorialized by the smoother space of multi-disciplinary, patient-centred healthcare. This process of ‘becoming other’ resonates in how the chronically ill accommodate changing identities, and collaboratively manage treatment decisions in increasingly accessible, interactive and rhizomatic information networks (networks that remain largely invisible yet are pervasive, and do not seek vertical structures of hierarchy but expand horizontally through associations).

### **The ‘e’-patient: An Overview**

Drawing on changing power relations in the clinical relationship alongside evolving cultures and technologies of communication, informed, connected, and empowered “e-Patienthood” (Ferguson, 2010) is the current expression of emerging forms of patient power. Digital communication has been credited with a range of democratic advances, eroding hierarchies between producers and consumers (Rheingold, 1992; Castells, 2000; Atton, 2004). Online health communications specifically is an expanding biopolitical arena, as patients mesh into expanding networks to exchange narratives, and potentially galvanise action from local grassroots to global levels. Through a range of online practices from everyday narrative exchange to active advocacy, these online actors contribute to participatory culture’s power to destabilise normative “regimes of truth” (Jenkins, cited in Burgess and Green, 2010: 122).

Hardt and Negri (2009)<sup>38</sup> outline what they see as a contemporary displacement of a traditional binary public/private divide (and its socio-political manifestations) with a 'common wealth' of networked communicative practices producing new forms of capital, for example *emotional* capital, redistributed through identification empathy online (similar to identification with characters in fictional narratives). Networked cultures are seen as re-shaping traditional social relations in a number of ways (Castells, 2000). Andreas Wittell for example draws on Bauman's (2000) concept of 'liquid modernity', in which network sociality substitutes traditional enduring *narrational* social relations with the continual integrations and disintegrations of *informational* exchange. Information does not necessarily structure into a story, remaining as data; yet, of course there are stories about information or data (Bleakley, 2005).

Exchanges in online support communities might support Wittell's view of "fleeting and transient, yet iterative social relations; of ephemeral but intense encounters" (Wittell, A., 2001: 51). The growth of knowledge exchange in online health support networks locates the internet as a significant archive of contemporary health care culture, supporting Lev Manovich's view of the database as a key form of cultural expression of the computer age (Manovich, 2001). It is no longer enough to question how various cultural practices (medicine for example) might be enhanced by new knowledge economies. Rather, it becomes necessary to consider the effects of digital technologies on our cultural identities in general or, as Sherry Turkle puts it, how they

<sup>38</sup> *Commonwealth* (2009) is the third of Hardt and Negri's trilogy of texts addressing the evolving concepts and practices of organizing of capital and power in late capitalism. It is preceded by *Multitude* (2004) and *Empire* (2001).



are shifting our “fundamental notions of who we are and what we need to do and who we should do it for” (Turkle, cited in Ferguson, 2007: xii).

From this evolving landscape emerges a powerful revolution in the hegemony of medical knowledge production/consumption, with the potential to subvert traditional power bases, as acknowledged by Ferguson’s prediction that “the principal protagonist of our next-generation healthcare system will not be a computerized doctor, but a well-wired patient” (Ferguson, 2007: xii). Patient-*centredness* (itself a hard-won subject position for patients<sup>39</sup>) is arguably in a process of displacement by patient-*connectedness* requiring some degree of identity (re)construction for both patients and clinicians alike. The challenge for acknowledged experts in coming to terms with the cultural and hierarchical shifts that new technologies can produce in their field is well-documented:

Really substantive innovations – the telephone, the copier, the automobile, the personal computer or the internet – are quite disruptive, drastically altering social practices. [So] our established experts may be those *least* capable of helping us find our way safely through the disruptive social innovations these new technologies will require (Brown, cited in Ferguson, 2007: 21).

US haematologist, Richard T. Penson and colleagues (Penson et al, 2002) researched the potential positive impact of online health support communities in the context of professional

<sup>39</sup> The term ‘patient-centred’, originally coined by Balint in 1969, expressed a belief that every patient “has to be understood as a unique human-being,” patient-centered medicine emerged as a descriptive account of how physicians should ideally interact and communicate with patients. See S. Saha et al. (2008) for an outline of the evolution of ‘patient centredness’ in their paper ‘Patient Centeredness, Cultural Competence and Healthcare Quality’ published in the *Journal of the International Medical Association*.

anxieties surrounding misinformation, concluding judicious internet use to be overwhelmingly positive and empowering for patients and, in some cases, professionals (Penson et al, 2002: 555). However, the imperative to view change through the lens of a culture within which actors are already situated can result in downplaying or actively resisting innovative developments, and the survey Translations in this chapter evidence a degree of reluctance among some clinicians to embrace the democratizing potential of modern medical communications currently encouraging patients “to access content, connect with others, and collaborate with others in ways never possible before” (Ferguson, 2007: 22). Others though are actively engaging with the cultural shifts in clinical relationships, even becoming key actors in online support networks, as this work reveals.

Patients may also resist or struggle with various elements of ‘e-patienthood’. The use of online support communities by e-patients is an emerging field of study from a number of perspectives (Maloney-Krichmar and Preece, 2005; Orgad, 2005; Leimesiter et al, 2006; Hoybe et. al, 2007). Whilst very few research projects conclude that online healthcare support has proved harmful, some have identified tensions including: uncritical assumptions of empowerment and agency as positive outcomes of online support (Sandaunet, 2007); social exclusivity in online support groups (Eun-Ok et al, 2007); narcissism and ‘ego-casting’ in online spaces (Rosen, 2004; Mahato, 2011; Faigley, 2001); insufficient proof of effectiveness (Eysenbach et al, 2004); and the potential of the internet to affirm a range of normative ideals (Pitts, 2004).

The following Translation section provides a quick snapshot of some of the dominant CLL nodes

used by survey respondents, from online support communities to social media before going on to explore online experiences and practices among respondents.

## Translation: Dominant Nodes in the CLL Networks

Survey questions opened with multiple choice selections for major sites used by respondents, drawing from a list of my own impression of the key nodes compiled from my own field-work, and inviting patients to tell me about any sites they used that I had omitted. Results can be seen in Figure 10 below:

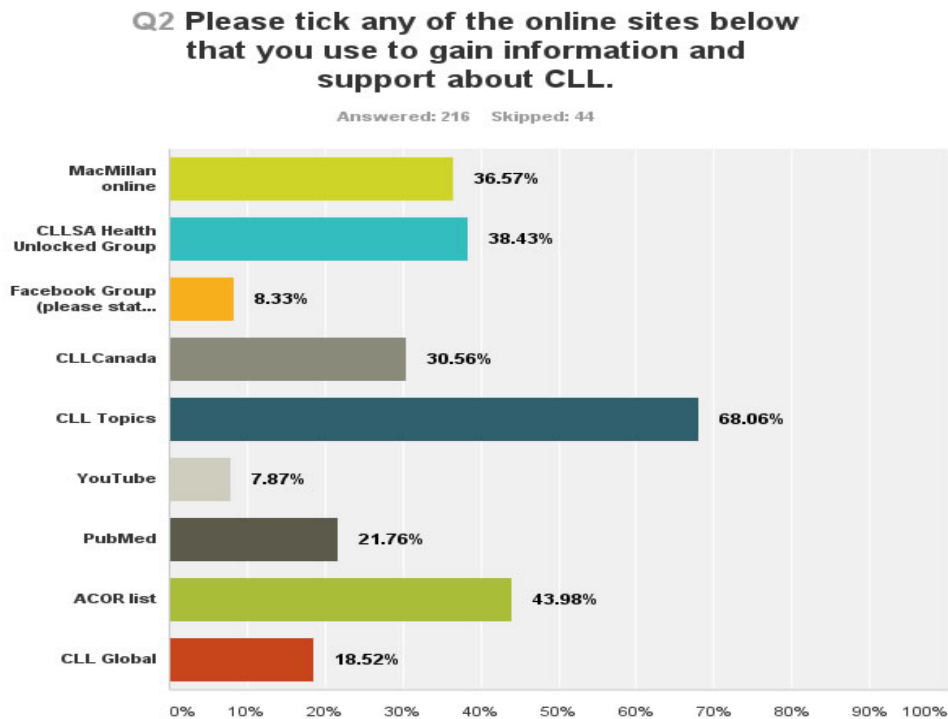


Figure 10: IN OUR BLOOD SURVEY (2012) Reported % use of online sites used regularly in 2012 by In Our Blood survey respondents to gain information and support about CLL [Graph].

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A plethora of site-specific comments such as the very small selection below demonstrate loyalty, trust and a sense of historical evolution/development in particular sites:

*It is fascinating to have watched the 1st acor and granny barb sites grow into such resources. I picked the clinical trial in 2000 based on information from these sites (IOB Survey Respondent 106).*

*I cannot imagine not having ACOR when I was diagnosed. I have been on the internet since its inception and ACOR was all there was at dx. It was a lifesaving experience (IOB Survey Respondent 30).*

*You have to be careful which sites you look at as some can scare the pants off you! I only look at MacMillan[sic] as I know it's a trustworthy site (IOB Survey Respondent 201).*

In addition to the % usage reported for the sites listed above by the 216 respondents answering the question, 77 respondents also used the comment section to report other sites used. (Please refer to Appendix 11 for the key alternative sites identified by respondents at the time of the survey, and a short narrative analysis of key sites and analytics observed through fieldwork in March, 2013).

Network activity is dynamic, with sites growing or fading in popularity over time due to a number of factors. Actor-Network-Theory disavows evaluating network quality on the basis of

raw numbers of participants alone, focusing on translations across *all* actors (persons, artefacts and ideas) involved in creating network activity:

Intermediaries fail to translate effectively, causing potential networks to stall, fade, collapse or crystallize (for example a website that deposits information but does not allow for interaction), where mediators (for example an interactive component on a website) facilitate translation between actors and the expansion of a network to produce more potent network effects (Bleakley, 2012).

Specific site functions and stability will be looked at more closely through the Translation sections of the themed chapters where I map the flow of selected narratives across sites. This brief snapshot of site usage at a given point in 2013 can only reveal the *range* of knowledge-sharing activity in the networks at the time. From dedicated research sites, through specialist sites with translational and interactive functions, to community forums and social networking, no *one* particular site or site-type provides *all* of the information and functionality required to keep the networks vibrant and to engender the flow of CLL narratives around them.

Human actors also work at different levels of 'e-patient' participation in the networks, from those who set up and maintain sites, creating hubs and connections, to those who simply read or 'lurk'. This work will reveal some of the key actors in the network as it unfolds, and the next section looks at survey responses to the question of individual participation levels.

## **Translation: Levels of Active Participation (Posters and Lurkers)**

There were 221 responses to the question about levels of participation, with 80 respondents commenting further on their activities.

In summary, 24 respondents (11%) claimed to 'actively' post online about CLL issues on a regular basis (more than six posts annually), with the largest group of 86 (40%) claiming 'occasional' posting. Not far behind them though were the 81(37%) of respondents who logged in to CLL sites regularly, but never posted. Bracketing this majority middle group of occasional posters and 'lurkers' were the 30 people (14%) at the other end of the participation scale who said they rarely visited CLL sites or posted online about their disease.

Responses vary widely from those who never post:

*I was not aware of any such website (IOB Survey Respondent 226).*

*I never contribute to sites online (IOB Survey Respondent 215).*

To those who contribute very frequently (daily in some cases):

*Post daily, as blog or in reply to questions or response to PMs generated by groups and individuals seeking answers or replies (IOB Survey Respondent 5).*

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The majority of people answering this question though claimed moderate levels of posting activity from monthly to 2-3 posts a year. Several respondents nuanced their answer by providing context around the triggering points for making a post:

*I read two lists every night, and also read Brian Koffman's blog almost every night. I post if I feel I have something to add to what has already been said. This can be either about my personal experience (CLL and breast cancer) or just trying to get a clarification. Maybe once or twice a month (IOB Survey Respondent 44).*

*My frequency depends on what is happening in my life. I was on W&W for 11 years before treatment. Now I am on partial remission and basically back on W&W (IOB Survey Respondent 226).*

*During my treatment and just prior to I posted more regularly now I mainly read (IOB Survey Respondent 100).*

Unsurprisingly, levels of online interaction for many CLL patients correlated with key milestones on a trajectory of disease progression and treatment interventions such as living in watch and wait, prognostic testing, treatment, relapse and dealing with secondary malignancies or co-morbidities.

Newly diagnosed respondents reported particularly high levels of activity as they seek to learn about the disease and its implications:

*Only diagnosed about 4 weeks ago, but CLLSA Health Unlocked Group looks good and I have already made 3 contributions (IOB Survey Respondent 131).*

*I am only recently diagnosed (14 Feb 2013) so I am using the communities to learn and get some support when I feel low, I also find it helps to write about feelings and support others too. I probably post around once a week for my own purposes and reply as I feel I need to others. I check the forums at least 3 to 4 times a day (IOB Survey Respondent 144).*

Some group members acknowledge an important role in making unconditional responses to any other member requesting information, whereas the following respondent calls for members to take responsibility for updating themselves on the basics before posting questions:

*I used to post on the CLLSA site but became discouraged that people did not read information already available before posting basic questions (IOB Survey Respondent 25).*

Comments such as this indicate a range of definitions of “support” amongst individuals using these groups, and the potential for disengagement amongst those members with a more autonomous approach to understanding the disease when interacting in support groups with those less well informed than themselves. It also indicates how the definition of “basic” questions might change as group members learn more about their disease. Another experienced user described using personal mailing facilities to contact individual forum members rather than making a public post:

*If I did this form 8 years ago I would say I did it daily, however these days I just read the post and hardly ever post, however I sometimes send private emails to those that I feel need support (IOB Survey Respondent 72).*



This response shows how frequency of interaction may lessen for those who have accommodated the disease into their lives – a phenomenon I have observed in my own engagement. It also indicates an interesting private/public distinction in communities where support interventions are not always perceived as best served by public forum postings where private messaging facilities are available. The issues of actual, perceived or imagined audience response to public postings will be explored later in the chapter in relation to reasons for non-posting, but responses showed how some novice members saw the process of acclimatizing to online debate as a learning curve requiring preparation through observation and modelling on current community approaches before taking the plunge:

*I have posted only once being fairly new to participatory sites, however, I feel will post more in the future. I do log in and read posts frequently thereby getting a feel about how such sites operate (IOB Survey Respondent 212).*

*It's a new experience sharing personal information/comments with 'strangers' so for me I need to read the type of posts and articles before I feel comfortable in participating in a more active way... (IOB Survey Respondent 212).*

As well as wanting to know the levels of participation amongst CLL patients online, I was interested in the motivations of those who did post.

## **Translation: What do People Say Online?**

101 respondents answered a question about the varying motivations behind their contributions. 39% reported sharing information and links with others. 63% reported posting to

seek advice for themselves. 61% said they posted about the physical and psychological impacts of living with CLL, and three respondents (3%) reported having their own CLL related blog, and 2 (2%) reported posting videos about CLL to YouTube.

Several respondents described posting as an altruistic pursuit -a means of helping other patients, and of appreciating and lending support to the contributions of their fellow members:

*I post to respond to others expressions of the impact of living with CLL. I post to express appreciation and commentary about anthers [sic.] writings (IOB Survey Respondent 67).*

*I was a caregiver, I generally write personally to new patients rather than post and tell them about CLL Topics & Updates - which was enormously helpful to us, as well as general info that might help them as newcomers (IOB Survey Respondent 42).*

*...moral support, especially for newcomers, and basic resources to start one's education, ways of dealing with being new, like taking a recording device to appointments, usually privately, connections to other resources or people who might be helpful (IOB Survey Respondent 20).*

The therapeutic value of 'reciprocal-helping' in support communities both on and offline has been noted in previous studies of online health communities (Maloney-Krichmar and Preece, 2005:219), and Preece and Ghazati conclude their work into online empathy with the observation that 'empathy appears to occur naturally' (although not necessarily exclusively) in those communities specifically set up for support amongst people with health issues (cited in Rice and Katz, 2001: 257). However, there is a range of 'house-styles' across the key communities, some more concerned with information sharing than social or emotional support.

In a study comparing information seeking effectiveness and perceived social support—on perceived empathy in online health communities set up by institutional health care organisations, the author concludes that “it is the information seeking effectiveness rather than the social support which affects ‘patient's perceived empathy in online health communities run by HCOs”<sup>40</sup> (Nambisan, P., 2011). A need to understand network activity within the contexts of the perceived motivations, aims and interface of specific sites is important.

Others cited more specific content, related to their own disease experience, such as secondary infections, and allergic reactions:

*reading and exchanging experiences of treatment and Dr. patient inter action on explanation of disease progression or side effects from infections etc. (IOB Survey Respondent 214).*

*Posted regarding an allergic reaction to antibiotic during treatment (IOB Survey Respondent 175).*

Postings are used to solicit and share information tailored to the poster's *particular* disease contexts and experiences. Archive facilities on sites such as ACOR accumulate rich repositories of discussion threads on specific disease aspects. These collaborative databases contribute significantly to disease knowledge through the potential for meta-analysis of a broad range of experience and knowledge not necessarily available through one-to-one patient/clinician

<sup>40</sup> P. Nambisan concluded that such communities need to focus on developing tools to enhance the flow of effective information seeking (Nambisan, 2011)

relationships (however experienced the physician might be). The issue of big-data sharing in online contexts will be explored further in the Treatment chapter.

Others were engaged in broader debates surrounding CLL related issues such as diet, nutritional supplements such as ECGC (green tea), curcumin, vitamin D<sup>41</sup>, and physical fitness:

*I am particularly interested in physical fitness and how it is affected by CLL or how it affects CLL (IOB Survey Respondent 173).*

The nature of sharing and mutual support demonstrated by much of the activity in online networks and reiterated in these comments speaks of a general ethos of advocacy at personal and community levels. Some in the networks however take on and espouse a more *directly* political level of advocacy. This respondent describes how they used posting as a means of political campaigning, lobbying the Canadian government for access to front line drugs in the treatment of CLL in specific states:

*As a member of CLLPAG I have written and lobbied the provincial Minister of Health re the lack of access to Rituxan except as a first line of defence. Ontario is the only province in Canada with such a restriction (IOB Survey Respondent 101).*

<sup>41</sup> Both curcumin (the active ingredient in the spice turmeric) and the green tea extract epigallocatechin-3-gallate (EGCG) have been shown to demonstrate marked effects on the apoptotic machinery in CLL. In their (2009) paper for the *Journal of Clinical Cancer Research*, Angelo and Kurzrock concluded that 'these results provide a preclinical foundation for future clinical use of these compounds in this disease'. Vitamin D insufficiency at diagnosis has also been associated with inferior time to treatment and overall survival in initial studies by Shanafelt et al. (2009), leading to calls for further studies in the field.

Julia Kennedy

As new treatments roll out, raising questions about funding and access, more CLL patients are becoming politically active in their advocacy and this will be explored in greater detail in the Treatment chapter.

The following response maps a trajectory of engagement from online information and plans to manage future disease progress using 'www' to face to face interactions with global specialists at a conference discovered online:

*At peace with diagnosis. The leukemia and lymphoma society was a great place to read and then research links to learn about CLL when first diagnosed from 2008-2009. Learned about an International CLL/lymphoma conference from this society-attended lectures in 2009- and met with top researchers, doctors, patients and survivors When I go from watch and wait to a change I would go to this site and start looking for updates on the www (IOB Survey Respondent 110).*

Using online sites to source conferences, expert care provision, or to connect with other patients and professionals offline is a commonly witnessed phenomenon across support networks, demonstrating potential for digital community engagement to mesh users into broader health support networks offline.

### **Translation: Non-Participation (Why People Don't Post)**

Almost as many respondents as those reporting the demonstrable benefits of active reciprocal engagement in online support networks claimed to visit sites regularly but not post, raising

questions about the nature and definition of 'engagement' in online communities. The phenomenon of 'participation inequality' is widespread and well documented, with an apparent spread across most online communities in which "90% of users are lurkers who never contribute, 9% of users contribute a little, and 1% of users account for almost all the action" (Nielsen, 2006).

Those respondents to the IOB survey claiming to actively read and engage with communities but never or rarely post gave a variety of reasons. 31% said it was 'too time-consuming'. Furthermore, a sense that too much time spent online might over-determine people's lives with their disease was relatively common in the written responses, with an ethos of just wanting to "get on with life" and not "dwell" on the disease:

*I very occasionally look online to see if my tiredness or perhaps various aches and pains may be attributed to this disease and shared by others - generally I would rather just get on with life until such time as I need treatment (IOB Survey Respondent 223).*

*I do not want to dwell on my CLL as I have responded well to 6 months of treatment and just want to get on with my life and stop thinking about it! (IOB Survey Respondent 220)*

Several respondents described avoiding direct participation as a strategy for reducing anxiety provoked by engaging with others' stories/experiences and, in some cases, of avoiding imposing their own experiences on others whose disease courses may be very different. Again, this is related to the heterogeneity of CLL and the fact that an individual's experiences and

disease course may be significantly different from that of other members:

*I don't use many sites as I believe that there is a lot of contradictory information and it only adds[sic] to the confusion and I find that some of the blogs are used to publish unhelpful information. I prefer to use sites like CLL Topics as it gives clear information that, in my case has been correct, and I am [sic] can discuss with my consultant. It is not some horror story from someone who has not listened to their consultant or diagnosis and has heard the words CLL or Leukaemia and have decided their lives is [sic] coming to an end, or everyone has to understand that their case is worse case and everything is doom and gloom. I believe that some of these sites are harmful and do more damage than good, that is why I do not use them (IOB Survey Respondent 172).*

This respondent expresses a belief that narrative sharing in support communities tends towards the negative, describing narratives therein as 'horror' stories, attributing them to people who have 'not listened to their consultant or diagnosis', but have responded to the word 'leukaemia' to jump to grim (and supposedly uninformed) conclusions about their mortality. Of course, CLL can and does result in grave illness or early death, so there may be an element of denial in this response, as in the perception of a kind of competitive mortality or attention seeking going on in the observation that '*everyone has to understand that their case is worse case and everything is doom and gloom*'. This respondent sees this as 'harmful', expressing a need to protect themselves from the less positive personal stories of others (with perhaps a more aggressive CLL than their own) by avoiding communities encouraging this kind of exchange.

It also reflects a preference for positive narratives and attitudes observed in previous work on online cancer communities (Orgad, 2005, 2006; Pitts 2004; Sharf 1997). Orgad's work on online communications in a breast cancer community noted that stories of death or despair were

excluded or re-framed by community 'veterans' into narratives of enablement and hope, the dominant community discourse being shaped into one about 'living with disease rather than dying from it' (Orgad, 2006: 892).

The extreme heterogeneity and differing rates of progression of CLL means that the range of immediate health concerns being faced by those in the same community can be considerable. It can be challenging to share a narrative disease space with others who are struggling for their lives if one's own disease is currently well controlled. However, an estimated 4,600 people died of CLL in the US alone in 2013, perhaps accounting for some of the 'horror' stories resisted by respondent 172.

The challenge of managing the less optimistic narratives they encountered online was recorded by several as a reason for non-participation. Others spoke of having to learn to manage the effects of encountering difficult narratives on their own anxieties about the future:

*Diagnosed 2008. Thought to have had CLL for up to 5 years before that. Took a while to work through shock and assimilate it all. Progressing very slowly so still on watch and wait. Find too much exposure to distress of others brings it all to the front of my mind to the extent I start to become unable to 'live for the day' (IOB Survey Respondent 179).*

*I don't find it helpful to read other people's treatment journeys. They do not usually come with a health warning up front and having lived with this disease for 4 years, through 3 rounds of treatment and a bone marrow transplant there is a degree of self-preservation required. As such I don't post either as my journey has been tricky and I wouldn't say that helpful. Perhaps that will change if I reach a period of stability but not yet unfortunately. I use the Internet mainly for factual research on drugs, side effects, conditions & research (IOB Survey Respondent 256).*



The latter respondent indicates that his or her concerns about coming into contact with distressing narratives which 'don't come with a health warning' keeps them from sharing his or her own difficult story online for fear of distressing others, or making them 'unable to live for the day' like the first respondent. This expresses the need to retain hope in the face of a chronic, unpredictable and life-threatening cancer, and the relationship between hope and information seeking behavior in cancer patients has been explored in previous research. As Geraldine Leydon and colleagues discovered in their in depth interview study of cancer patients' information needs and information seeking behavior, hope and fear are closely related, many patients oscillating between periods of information exposure and avoidance. Strategies such as cessation of research, silence, and self-censorship enabled patients to "circumvent negative information about their illness, which poses a constant threat to hope" (Leydon et al., 2000: 913).

A sense that the heterogeneous nature of the disease was not always accommodated effectively in forums created a significant point of tension for the following user, who came to feel that they could not post "honestly" about their experiences:

*I found out fairly early on that because CLL is a disease that has a different course in some people i.e. some people have a very indolent version and are much older, well into their 70's when diagnosed, that they completely misunderstood some of the emotional issues I had with a more progressive course of CLL and being diagnosed at a relatively young age (50). I started to feel as if I was moaning and not being positive and I found this distressing and patronising and that just made me more angry. I still work, even though the fatigue is quite severe. I was not annoyed at the responses on a personal level, I just realised that even people with the same disease can be quite ignorant because of the very heterogeneous nature of CLL itself. I was actually honest once on the site about one of the comments made (not in any way horrid) and someone actually left*

*the online forum. There are some wonderful people who are totally and fully supportive but because of my experience I found it difficult to continue to contribute as I had done. Because I work and get very tired, I also found it exhausting to be online too often talking to others, although I do read the posts (IOB Survey Respondent 19).*

The question of imagined audience perception when posting to a community is an important issue, and was raised by several respondents when talking about their reasons for non-posting. This is reflected by the 27% of respondents who didn't post as they were 'worried about upsetting others with the 'wrong' comment/issues'. The practice of regulation or self-censorship of both reading and writing honest narratives of the challenges of living with CLL has very real implications for those patients actively seeking online support with issues of aggressive progression, death and dying. As noted in a previous context, member perceptions that affirmations of empowerment and agency were the *only* available narrative positions in self-help groups was a significant barrier to participation (Sandaunet, 2007: 142). The tensions between the need to retain hope and the need to discuss the challenging issues faced by those with progressive or poorly controlled disease in CLL communities is a perennial problem across some sites, and requires further focus which could extrapolate to a range of online health communities.

The lack of visual cues indicating age, race, gender and general health amongst posters online in tandem with heterogeneity of disease experience troubled this respondent:

*I prefer face-to-face contact when discussing such a personal issue, given the different experiences people go through, I feel that one size does not fit all and doing over the internet people are more likely to force a theory than they would if talking face-to-face*

*i.e. if a 44 year old female was having one experience, it could be very different from a 64 year old male's experience. This would be quite obvious if people could see each other, but not so if contributing to a discussion online (IOB Survey Respondent 163).*

Defining homophily as a desire to communicate and increased perceived empathy between sources and receivers who are 'alike' (similar life experiences and life events), Nambisan (2011) notes that patient absorption of health information and satisfaction with group interactions are enhanced when acquired from people who are similar or have 'similar disease experience' (Nambisan, 2011). Whilst being a 'CLL patient' is a universal title amongst those in the communities, the experience of CLL as a disease is far from universal. As demonstrated, the lack of homophily amongst community members can act to undermine group satisfaction and empathy, and lead in some cases to total disengagement.

Of the 39% simply 'not comfortable' posting online about CLL, comments indicated concerns about personal boundaries surrounding the private nature of personal medical detail, and the public anonymous nature of online forum communication:

*Don't tend to open up to others in general and never so on medical matters! (IOB Survey Respondent 228)*

*I have never felt any inclination to share my experience other than face-to-face or with people I know well (IOB Survey Respondent 205).*

*I am shy about speaking in public, this feels the same to me (IOB Survey Respondent 42).*

Julia Kennedy

Additional comments indicated concerns about not being articulate enough, and having nothing new to add. A clear thread of generalized discomfort with online discussion emerged. Whilst many CLL patients have comfortably migrated online, those in the CLL demographic are not digital natives:

*I am about to turn 71; I am, nevertheless, very computer/web savvy and use the internet all the time. However, I find that I am generally uncomfortable about expressing myself to such a large, and unknown, audience. I prefer to PM when necessary, although I occasionally do post. I am somewhat ashamed of not posting more, since I gain so much from what many others contribute (IOB Survey Respondent 26).*

Again, the private/public distinction in contexts of an imagined audience is apparent in a preference for private messaging. Also of note is the guilt expressed at adopting the role of recipient and not donor in a perceived 'one-way relationship' of support. Others felt that they had little to contribute themselves, but much to learn from more experienced members in a perceived hierarchy of community knowledge:

*I am mostly a reader, since most of the issues are educational and discussed by patients with much more experience and knowledge than myself (IOB Survey Respondent 96).*

*At just 30 months into this "experience," and despite all my personal research, I am still tremendously ignorant into the actual course of this disease, my prognosis for leading a semi-normal life, and the emerging courses of treatment. I am still learning but I have little of value to contribute to others with the same disease (IOB Survey Respondent 82).*

Several respondents made the point that infrequent posting did not relate to their engagement with the forums as readers, going against the grain of 'the preconceived notion that you must

be an active poster to be part of a community.' (Nonnecke and Preece, 1999):

*Rarely post--do not like to live my life in public; however, I always read, and occasionally contribute if I think I have something useful to say (IOB Survey Respondent 26).*

*Post occasionally; read every day (IOB Survey Respondent 37).*

It must be acknowledged however that not everybody using the CLL networks seeks this sense of community. The desire to find information without participatory communication was expressed quite clearly by this respondent:

*I use the sites only to get information about CLL and to keep up to date with research etc, I do not feel the need to communicate with other people with CLL (IOB Survey Respondent 195).*

Finally, 14% were concerned enough about confidentiality and privacy issues online not to post as indicated by the following patient considering site types they might be willing to contribute to in the future:

*I'm a Watch & Wait lurker. When I have something to ask or something to say, I'll post on forums that have a modicum of confidentiality (e.g. NOT Facebook) (IOB Survey Respondent 69).*

## **Translation: Impact on Life with CLL (Does Online Information Help?)**

Whether active posters or not, I was interested in the extent to which respondents felt more informed as a result of online use. In total, 225 responses were recorded to the question, 'Do you feel that your internet use surrounding CLL has made you into a more informed patient?' Of those, 208 (93%) said it did, 4 (2%) said it didn't, and 13 (6%) said they weren't sure.

More important to understand however is and whether and how being informed might translate into a positive impact on living with CLL. Asked if online information helped them to live with CLL, 187 (83%) of the 223 responses declared having more information as helpful in living with the disease. Thirty three people (15%) felt that it helped them some of the time, sometimes, whereas a minority of 6 people (3%) answered no to this question as shown in Figure 11.

### Q7 Do you think that having more information helps you to deal with living with the disease?

Answered: 225 Skipped: 35

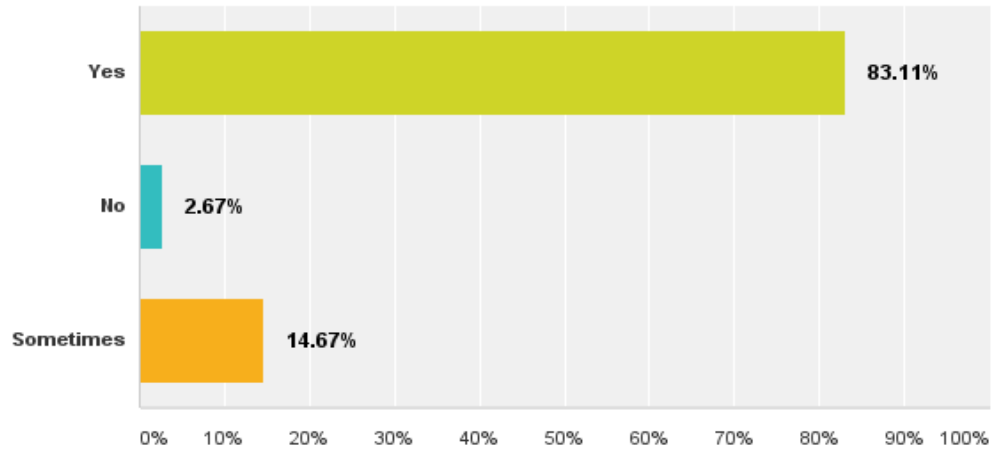


Figure 11: IN OUR BLOOD SURVEY (2012) % responses reported by In Our Blood survey responses to Q7 - Do you think that having more information helps you to live with CLL? [Graph].

Amongst the responses, a number of themes emerged.

For some, simply having information (whatever its nature) reduced overall anxiety and afforded some sense of being in control of the situation:

*The known is less scary than the unknown; better a cobra in a flashlight beam than stumbling in the dark wondering where the cobra is! (IOB Survey Respondent 111)*

*... feel much more in control of my life since I have begun reading the various lists to which I belong. I had been diagnosed for a year and a half before I found the various lists; the difference in my sense of well-being before and after is striking (IOB Survey Respondent 26).*

It is remarkable that patients express a sense of comparative relief once having found sources of information on the internet, despite already being diagnosed with CLL and having been in the care of a medical team for some time:

*I've had over 15 years of CLL -- doctor visits, chemo, non-chemo treatments -- and ONLY online information really tells me what is happening and what can be done. Far more detailed than doctor visits, hospital stays, etc. My confidence over the years has been bolstered by online information. I've never been "afraid" of CLL because of what I learn online from reputable sources (IOB Survey Respondent 17).*

This certainly raises questions about the levels of information many CLL patients are getting from their clinicians alone. A group of 'watch and wait' CLL patients surveyed in 2011 reported feeling that they were not treated as being really 'ill' by their consultants, with a consequent lack of provision for information and emotional support. Whilst the authors (including haematologists) acknowledge that it can sometimes be a clinical strategy not to concern patients with possibilities of progress that might not transpire, they also cite the conclusion of a meta-analysis of the literature on oncological clinical relationships (Arora, 2013) that underestimating patients' information needs can cause unnecessary confusion and uncertainty, concluding themselves that CLL 'patients in our study (and many others) routinely say that they would prefer information.' (Evans et al, 2011: 9). This paper is an important circulating narrative in the networks and will be presented as a Translation in the Diagnosis chapter.



Julia Kennedy

Across the support networks, and in the survey, patients treated by CLL specialists rather than general 'haem-oncs' reported feeling more informed about current CLL research and treatments. Geographical location often dictates access to specialists and research centres:

*Since I had no local specialist, knowing about the disease, its progress, and the treatment options helped me make informed choices when the time came for treatment. Furthermore, society is so heavily committed to the concept of treating cancer immediately, it helped to have widespread anecdotal support about the wisdom of "watch and wait", which I did for 7 years (IOB Survey Respondent 54).*

*I firmly believe that one is responsible for one's own health and should know everything possible about diagnosed conditions. Also, since I do not live near any CLL experts, I rely on internet information to keep me up to date (IOB Survey Respondent 37).*

Aside from access to informed 'specialist' online disease communities proving effective in enabling patients to negotiate broader cultural discourses of disease, this response highlights the role of online knowledge sharing in going some way towards addressing inequalities in access to specialist clinical knowledge in the clinical setting, and this will be explored in greater detail in the themed chapters. As well as filling the information gap for those already in care, for the newly diagnosed, information seeking online can provide a means of pro-actively opening informed dialogue with clinicians from the outset:

*I have learnt a lot about the condition and symptoms, received some great advice and have lots of questions for my first Hematology appointment on 12th April (IOB Survey Respondent 144).*

Julia Kennedy

Knowing what questions to ask at a consultation, particularly when newly diagnosed or facing disease progression, is a common forum topic, listed by the following respondent as one of several ways in which online narrative sharing has helped them to live with CLL:

*It has helped in recognizing shared experiences what is normal, how to live better with and cope. How to: Understand protocols and standard of care and how best to work with the system. Understand my rights and realize expectations How and what questions to ask medics How to respond to a given situation (IOB Survey Respondent 5).*

The theme of supplementing information from time-limited clinical encounters through clinical interaction continues in responses. Pressures on clinical time forestall extensive discussion with consultants in clinics, and being informed through online interaction was employed as a strategy for getting the most out of the clinical relationship:

*My docs have only a little time. I need to know the big picture, review what I have forgotten, research something new to me, and read research abstracts and papers (IOB Survey Respondent 64).*

Limited clinic time wasn't perceived as the only obstacle to satisfactory clinical communications however, with significant numbers citing poor communication from their clinicians as necessitating knowledge seeking online:

*Knowledge truly is power- especially in dealing with Oncologists who don't always communicate effectively or who do not really disclose everything that may be useful to me in making medical decisions (IOB Survey Respondent 82).*

*very little information given at hospital visits about the latest developments [sic] for CLL treatment. In fact consultant takes the view not to worry about treatments until [sic] they become necessary! I feel far better having gained information about current treatments and the future proposals (IOB Survey Respondent 153).*

*If it wasn't for online I would no [sic] little to nothing about this disease. Although my onc is a nice guy I feel his attitude is "trust me because I'm the expert and I will tell you what you NEED to know" (IOB Survey Respondent 151).*

*Can't imagine how I would have coped otherwise. The info I get otherwise is at best inadequate, and sometimes just wrong (IOB Survey Respondent 148).*

Learning online can be challenging however, requiring considerable investment in time, not to mention the ability to absorb, select and differentiate between multiple complex materials available:

*Medical professionals are not the most willing communicators so an in depth understanding of an individual's unique CLL experience is usually obtained by searching, reading and absorbing over time the information that can really only be accessed on the internet. It depends on just how much someone wants to invest in the process (IOB Survey Respondent 96).*

'E-patients' adopt an active role in their own care (Ferguson, 2010). Through all of these responses runs a theme of knowledge seeking online that translates into negotiating, improving on, or supplementing the clinical encounter. It is about pro-activity, and taking some control:

*My aim is to actively share in the management of my illness - something you cannot easily do without a reasonable knowledge of the illness, its effects, progress and management.. I will not accept being 'done unto' (IOB Survey Respondent 128).*

*Absolutely, it is essential to be proactive in dealing with this disease. I took charge of my CLL from day 1, when my local lab misread my biopsy results. I read everything I can about the disease, including the latest treatments (clinical trials and others), the movers and shakers in the field, and more. I attend CLL conferences annually for up-to-date info (IOB Survey Respondent 123).*

Access to resources addressing alternative approaches to treatment was also raised as a benefit of online engagement:

*There are many points regarding alternative therapies and/or treatments that are not available from doctors. They will insist on following golden rules and treatments proven from clinical trials, but sometimes there are alternative options one could take, depending on prognostic factors (IOB Survey Respondent 96).*

Online networks accommodate a broader range of views than might the traditional clinical encounter, as the “erection of boundaries around what might be termed ‘orthodox’ or ‘legitimate’ knowledge and the ‘non-orthodox’ does not necessarily exclude both from occupying space within the Internet” (Hardey, 2001: 402). The above respondent is careful to include the proviso about prognostic factors in relation to taking alternative options however, and most CLL sites and discussions are at pains to separate out those approaches considered ‘alternative’ from more mainstream or ‘legitimized’ approaches to treatment and care. The Acor group for example has formalized its approach by keeping all ‘alternative’ treatment discussions off its main list, having set up a dedicated and separate list for these discussions. The use of some ‘natural’ products to treat CLL - such as ECGC found in green tea, and Vitamin D have a long history of debate across the networks, to some extent straddling the divide

between mainstream and alternative, but both having been studied to some extent in small scale trials and therefore legitimized as evidence-based.

Aside from personal learning and empowerment, the sense of community and collaboration inherent in online support groups was writ large across many of the responses:

*It helps me consider matters I might not have thought of on my own and it makes me feel part of a larger community with something shared rather than a solitary sufferer (IOB Survey Respondent 73).*

*Without much support from my husband, I don't know how I would have survived without the constant caring and support I get from the ACOR list I belong to (IOB Survey Respondent 78).*

*My reason for keeping in touch with CLLSA, if I'm honest, is to check how I compare with other people suffering this condition. I rely mainly from my haematologist team, for support and information (IOB Survey Respondent 251).*

*CLL is a rare condition that can also impact your sociability due to increased infection risk. How it progresses also varies greatly. Its rarity unfortunately means that patients can be provided with inappropriate treatment due to lack of experience with the condition by medical professionals. On line communities dramatically improve your chances of finding other people with whom you can share your journey, benefiting from the experiences of others and helping others to avoid the complications you've had. They also provide you with a means to reassure yourself that you are being offered appropriate treatment, or support to seek out better health services should that prove necessary (IOB Survey Respondent 4).*

*More information, especially on other people's experiences can help the "isolation" felt by most CLL patients at some time (IOB Survey Respondent 178).*

*I can communicate with fellow sufferers who show a lot more compassion and in some cases understanding of CLL than my Haematologist [sic] does. I get Good advice and its*

*[sic] also helps me appear more than [sic] just a helpless patient at clinic appointments. I feel empowered and i thank god i live with the disease in the time of the internet (IOB Survey Respondent 145).*

*Not so much about information for me support and knowing there are others having same experiences (IOB Survey Respondent 129).*

The positive social impact of online communities on cancer patients is well documented (Buis, 2008; Penson et al, 2002; Reeves, 2000; Hoybe et al., 2005). These responses illuminate the sense of isolation experienced by many CLL patients, and the profoundly beneficial impact that online community participation has had on that for them.

Tom Ferguson defines the e-patient as empowered and ‘informed’. However, it is clear that the level of information patients can deal with is dependent on individual levels of health literacy. CLL communities accommodate members discussing the disease at extremely high levels of scientific knowledge, alongside others without the knowledge or language required to participate at the same level. This left some feeling alienated or excluded by the technical detail, although still finding more emotional disclosures useful:

*I struggle with the detail - a lot of people comment in detail about b cells and things like that. It is too much information. I do appreciate though when people say how they feel it is reassuring to know I am not on my own when I feel rubbish! (IOB Survey Respondent 199)*

Alienation wasn’t the only response to technical exclusion though. The following respondent describes a strategy of befriending others in the network more medically literate than

themselves, and thus able to provide translations:

*While I don't understand much of the very technical information sometimes posted or in links, I feel that I am reasonably up to date on what's current and up and coming treatment wise, as well as how to interpret my labs, etc., and I have developed friendships with people who do understand the very technical reports and know that they can and will explain them if I ever need more information (IOB Survey Respondent 20).*

Those technically competent individuals tend to become key actors in communities, circulating research papers and important CLL news into local nodes across a global network, and bringing them into contact with the everyday lives and stories of support community members through the intermediary function of the digital platforms hosting various sites.

### **Translation: When Knowledge isn't *Always* Power...**

Whilst a sense of empowerment, control, and connection was expressed widely across the significant majority of positive responses, some acknowledged the challenge of confronting information that might not always be positive:

*Sometimes, periodically it depresses me other time panics me so I take a breather and come back later (IOB Survey Respondent 77).*

*It's a question of extracting the level of detail I need when I am feeling upbeat enough to deal with the inevitable negatives I come across! (IOB Survey Respondent 257)*

*sometimes too much information about what will happen as the disease progresses is too scary for me - I know I will have to face it but the knowledge of where to find the information when I need it is sufficient for me right now (IOB Survey Respondent 247).*

*I may not particularly like what I might find but knowing gives me the opportunity to at least adjust or perhaps put up some resistance to what might be or about to be happening. The only trouble with the Ostrich Syndrome is that it leaves a certain part of your anatomy exposed (IOB Survey Respondent 231).*

*I have researched my own bone marrow biopsy results and found some distressing information from research papers regarding my own perceived position. This made me more scared and a little depressed about my future (IOB Survey Respondent 19).*

A number of respondents claimed that internet use did nothing to help them live with CLL.

Gatekeeping information within very defined or hierarchical structures, whether at professional or online community levels, can be seen as a constraining factor in the democratization of knowledge. However, many respondents remarked on the obverse experience of information overload when the brakes are taken off the flow of information in networks:

*There is the possibility of information overload and a sense of 'coming to me sometime soon' feeling. Pure information for the sake of it can be daunting, i.e. percentage of people with CLL who go on to contract secondary cancers and their reduced OST etc. There are times when purist technical stuff has little applicable benefit and can cause alarm and generate anxiety. Some information should be restricted to clinicians and not used simply to inform patients if it can cause nothing but anxiety (IOB Survey Respondent 14).*

This respondent articulates a number of concerns associated with what might metaphorically be described as drinking from the fire-hose of CLL information online. Skills are required to



negotiate the fine line between quenching a thirst for knowledge, and drowning in it. Again we see the issue of aggregate statistics, this time around susceptibility to secondary cancers, implying a second order of risk for CLL patients. In referring to such knowledge as ‘pure’, ‘purist’, and ‘information for the sake of it’ the respondent implies its uselessness in the applied sense, and links it to raised anxiety levels. In their closing comment, the respondent articulates a wish to make it stop – to put the genie of unalloyed information flow back firmly into the bottle of professional control. The art of discerning and managing the relevance of unregulated information in the networks to one’s own life is a difficult one, and whilst some learn to negotiate that, for others it translates ultimately to a lack of trust:

*There is so much conflicting information that I feel it is difficult to trust any of it (IOB Survey Respondent 156).*

*However, as you will know most of the net is not peer reviewed. That means that for the 'ordinary person' (no scientific back ground, no medical or science qualifications) it is a question of the loudest voice wins. So many people believe what is actually incorrect. This can be subtly incorrect, or just an emphasis on useless aspects or ideas (IOB Survey Respondent 168).*

Whilst this may be true for individuals researching alone from databases and sources in the network, this work also evidences high levels of engagement with technical and medical information in the more dialogic spaces of the community. Support networks are bringing together highly competent lay people with professionals across a range of medical and related disciplines so an extremely well-informed and robust level of debate filters down into many of those communities forming the most vibrant nodes in the network, and identified as popular

sites by the survey respondents. Furthermore, that information does not remain external to the clinical relationships that patients have with their own doctors, allowing (in the best case scenario where doctors are open to collaborative relationships with their patients) for the professional experience and knowledge of the clinician to mediate or translate online information into the individual clinical context of a particular patient. Highly competent patients might also bring new information to their doctors in a circular flow of online/offline narrative exchange.

### **Translation: Impact of Digital Knowledge on Clinical Relationship**

Decreasing respect for the hierarchies of knowledge and expertise in medicine has produced internet users comfortable to seek information beyond that deemed suitable for a 'lay' audience (Hardey, 2001:402). Ferguson (2000) observes that the chronically ill online can display 'impressive' knowledge of their own disease, functioning not only as valuable resources for other patients, but also as 'valuable resources and allies for health professionals' (Ferguson, 2000: X). I was interested in testing out the effects that online narrative sharing practices were having on respondents' own clinical relationships. Two hundred and twenty respondents answered the question 'do you discuss what you learn online with your doctors?', and 158 chose to expand on their response.

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One hundred and seventy six (79%) of the 220 respondents answering the question said they did discuss online information with their doctors, the remaining 46 (21%) did not. Text responses indicated overwhelmingly positive experiences with clinician responses to their online learning. Seventy three per cent (114) of the 158 text responses reported positive experiences, albeit that those positive experiences were inflected in various ways reflecting some interesting themes for exploration in this section. Sixteen per cent (25 people) reported neutral experiences (neither especially positive nor negative), and 17 people (11%) reported negative experiences.

One respondent took the time to reflect on this question in relation to the traditional clinician/patient relationship, making insightful observations about the potential threat that informed patients might pose to doctors, and the strategies they may adopt to deal with it:

*This is the biggest issue for the patient/doctor relationship I believe. It's probably much easier to be a passive, accepting patient (not necessarily safer though!) and it challenges the clinical 'mentality' that patients may even have read beyond their level on their subject. The fact that patients also understand the information and want to discuss it's [sic]relevance to their care can make doctors resort to their fall-back position of 'a little knowledge is dangerous'. With CLL, it's been a Cinderella subject for so long that I think patients have seized the initiative. I've found the Consultant happy to discuss research, developments etc. but possibly more resistance with his junior staff who possibly feel more threatened and surprised. It's balancing being a 'know-all' with fighting for the very best services and maintaining a good relationship with the clinical team. Patients who put on the nightie, look suitably afraid but grateful probably make the easiest patients. My GP admits 'I challenge [sic] him' and he enjoys it! (IOB Survey Respondent 14)*

Having to negotiate a balance between appearing too “pushy” and demanding the best treatment and services available is well articulated in this response. Patients who are active

researchers at home have reported actively performing a passive recipient role in the clinic to avoid 'the negative reactions they anticipated receiving from physicians' (Kivits, 2006:279). Respondent anxiety about being perceived as reading 'beyond their level' is supported by observations in the literature that informed and connected online patients can be treated with hostility or irritation by doctors who label them as "over-informed" or "problem" patients (Broom, 2005:336). Perceived pressure to be a "compliant" patient is also acknowledged by this respondent, although keeping informed is seen as having improved the clinical relationship, albeit described as a somewhat grudging resignation on the part of the doctor:

*My doctor doesn't seem interested in my knowledge, just wants me to be a compliant patient. I think this is due to not having enough time, too many patients to see each day. But my understanding and knowledge do make it easier for us to work together. I have emailed and phoned her as well as seeing her at the clinic: she's approachable and answers all my questions but not in detail, often with a 'leave it to us to know what we're doing' tone (IOB Survey Respondent 15).*

Demands on clinical time raised by this respondent appear in the literature as a significant factor in perceived physician resistance to engaging with informed patients in clinical settings with physicians concerned about "the time-consuming effort required to contextualize and interpret information for patients" (Ahmad et al., cited in Jacobson, 2007: 5)<sup>42</sup>. Despite general positivity to the increased understanding of disease demonstrated by patients researching

<sup>42</sup> Taken from a Canadian meta-analysis of work studying the effect of the internet on empowering the physician-patient relationship (Jacobson, 2007: 5)

online<sup>43</sup>, doctors calculated that engaging with informed patients added an average of 10 minutes to the clinical meeting (Helft et al., 2003: 946). A sense that doctors might eventually adjust to patients' increased knowledge and its attendant demands was commonly reported, demonstrating an evolution in cultural attitudes to clinical relationships, although variations across medical team members persist for some:

*My doctor in the beginning wanted me off the internet to stop scaring myself, but she has come to trust my judgment and now have ongoing discussions about trials, etc. (IOB Survey Respondent 66).*

*Ten years ago was different, however as the years went by and some consultants learn to treat patients as part of the team, being well informed helped...(IOB Survey Respondent 72).*

*My doctors (Hematologist and Family practioner) [sic] have both commented that I know more about CLL than they do. They are glad that I am a proactive patient (IOB Survey Respondent 94).*

*The ones I have now seem to engage me without being threatened by my lack of intimidation in their presence. Doctors vary in this regard; some are "take charge" and/or "listen to the expert-me" to the point of rudeness (IOB Survey Respondent 111).*

*My GP is fine and supports me very well. The head of team at Cancer Care encourages an informed approach. Occasional locum does not and likes to patronise. It has given me confidence to prepare my questions and ask for copies of letters to GP and blood tests (IOB Survey Respondent 179).*

<sup>43</sup> As demonstrated in a study of clinicians' engagement with informed online patients in clinical settings, carried out by Helft et al (2003).

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The issue of perceived “threat” to clinicians from online knowledge-sharing among patients continues in responses to this question, not always attributable simply to subverting traditional knowledge hierarchies. Clinicians may also worry about becoming subject to personal criticisms by patients online, adding another dimension to clinical attitudes to digital patient empowerment:

*My doctor makes a point of not subscribing to any of the lists (she says she is afraid she might read something negative about herself--though that is never the case, in fact; she's very popular). However, she is willing to talk to me about anything I've learned or have questions about. She seems to be one of those doctors who tells her patients as much as she thinks they can handle; she knows I'm informed, so she is pretty straight with me (IOB Survey Respondent 26).*

As medicine enters the arena of online consumer networks, it is unsurprising that clinicians might fear negative feedback from disgruntled patients. A 2012 study concluded that, whilst the practice of patient ratings of clinicians was becoming more widespread, there was in fact ‘no evidence that they are dominated by disgruntled patients’ (Gao et al, 2012), although the following respondent indicates perhaps why some clinicians may be worried if informed patienthood might reveal gaps in their knowledge:

*Currently, the reading up on CLL on-line has helped to realized that my Hematologist does not seem to know much about CLL as he is unable to answer the questions I ask (IOB Survey Respondent 71).*

Again, patient dissatisfaction with clinical knowledge translated into strategic response in many cases, ranging from the extreme measure of changing doctors altogether to the kind of pro-

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active collaborative approach to improving clinical knowledge described by the following respondent living in an area not serviced by a CLL specialist:

*We have no experts in Atlanta. I went to SanDiego twice for better advice. I have a support/discussion group here and we tried to get all CLLers to use Dr. xxx [name redacted by me]. This way she might become more "expert." No such luck. I emailed her 3x about PCI 32765 and at my last IVIG she didn't know yet what it was. I changed doctors the next month, after 10 years with her. My new condition requires more expertise now (IOB Survey Respondent 30).*

## **Translation: How Patients Employ Knowledge in the Clinical Setting**

Patients described a range of practices for employing knowledge gained online during consultations. For some, it provided the context required to make sense of clinical decisions, advice and results:

*It gives me context, more than anything. My range of understanding has expanded a great deal over the 18 months since my diagnosis, so I feel more comfortable talking about my blood tests and about possible future treatment options (IOB Survey Respondent 117).*

*...I am happy that what the doctors say is in agreement with what I understand from the internet (IOB Survey Respondent 45).*

*I ask better questions and understand their answers better (IOB Survey Respondent 255).*

*What I learn online gives me insights to better understand what doctors are telling me. I don't feel a need to cite the online material. I just have much more confidence in*

*dialoguing about my CLL (IOB Survey Respondent 17).*

Doctors have noted the positive elements for informed patients' sense of control over their disease management inherent in an ability to engage in "more equal, intellectual discussions" (Helft et al., 2003: 945). The following response shows how informed patients may feel confident to take the lead in a frank dialogue concerning outcomes that doctors might have been reluctant to initiate:

*Doctors seem to not want to tell you the bad things only the not so bad. Finding the bad things on line allows me to get them to open up (IOB Survey Respondent 56).*

Others used their information in much more pro-active ways to take a lead on their treatment decisions and choices, including changing clinicians where they felt this to be appropriate:

*MY CURRENT DR. WAS SURPRISED ABOUT MY LEVEL OF KNOWLEDGE CONCERNING THE DISEASE. SHE IS GLAD I USE THE INTERNET BECAUSE I HAVE ALERTED HER TO SOME THINGS THAT SHE WAS NOT AWARE OF. SHE WAS GOING TO USE FCR FOR MY TREATMENT, BUT DUE TO MY FOLLOWING DR. HAMBLIN'S ACOR ADVISE, I PURSUADED HER TO USE CHLORAMBUCIL/RITUXAN. SHE IS HAPPY I WENT THAT ROUTE BECAUSE SHE SAID SHE HAS NEVER HAD A PATIENT THAT RESPONDED TO THAT TREATMENT WITH SUCH SUCCESS. I AM APPROACHING A 3 YEAR REMISSION WITH ONLY A VERY BARE MINIMUM RESIDUAL DISEASE, ACCORDING TO BMB (IOB Survey Respondent 59).*

*My local general Hem/Onc commented that I was "a singularly well-informed patient." Since he confessed that he had never treated a CLL patient, that they mostly "die with the disease instead of from it", most of my information from the internet was more up-to-date than his. He was happy to do the extra tests I requested, and to discuss the results with me, and when treatment time came, happily sent my records to the CLL specialist I chose. When I saw the specialist, he was pleased that I understood my options, and I was able to begin a clinical trial immediately (IOB Survey Respondent 54).*



*Skin specialist now schedules regular check-up due to increased risk of skin cancer (IOB Survey Respondent 49).*

*...diagnosed in 2008 I was referred when the level doubled in 6 months to the local Haematology unit in May 2011. Monthly blood tests continued until Sept 2012. At that point having had 3 infections and a count of over 200 I asked about treatment and was assured all was well. At that point I used cllsa website to find another consultant and got myself transferred (IOB Survey Respondent 226).*

*I basically tell the doctors what is required (IOB Survey Respondent 117).*

Respondents commonly reported sharing links to interesting studies with their consultants, and downloading research papers to take to clinic. For one respondent, this activity led to an advisory role for new patients at their local hospital, the kind of scheme now legitimized by NHS hospitals in the UK as part of the Expert Patients Programme<sup>44</sup> for those living with chronic disease:

*Many of my questions to my CLL Specialist regarding my CLL Diagnosis are based upon information I learned. Additionally, I also share info learned online with my GP giving her the URL to the reference materials (IOB Survey Respondent 124).*

*My doctor knows that I'm very involved and has connected me with newer patients (with my permission), as has have the social workers at UCLA. My other specialists often ask me questions about CLL, as they also know that I do a lot of reading, attend conferences, etc. I have provided them with booklets, reports, etc. regarding CLL in general and specific questions they might have or issues that I feel need to be addressed (IOB Survey Respondent 20).*

<sup>44</sup> For further information about the Expert Patient Programme in the UK see, <http://www.nhs.uk/NHSEngland/AboutNHSServices/doctors/Pages/expert-patients-programme.aspx>

For some respondents, the experience of sharing knowledge with their clinicians was simply a positive one, and actively encouraged. This seems particularly to be the case where clinicians are already acknowledged as global experts in their own right:

*My Dr. reacts very positively to this as he is a world-renowned specialist in CLL. He encourages his patients to be well-informed on the latest treatments available (IOB Survey Respondent 93).*

*CLL medical experts are often academically inclined. A patient orientated discussion can therefore become a 'conversation between experts'. Most enjoy this (IOB Survey Respondent 254).*

*My oncologist is fine with it. Otherwise, I would find a different doctor (IOB Survey Respondent 124).*

Despite many overwhelmingly positive responses, some respondents reported very negative experiences:

*They are not interested really. Standard of CLL w an w care is minimal. You have to be pushy to get answers. Get much more information from informed websites and own research (IOB Survey Respondent 169).*

*My doctor normally does not really support or encourage information such as all of the available prognostic tests or alternative natural therapies that could have a small effect on disease progression (IOB Survey Respondent 96).*

*The doctors did not seem interested at all in what I learned on line. One doctor actually seemed amused (IOB Survey Respondent 33).*

A degree of lag in the evolution of the medical profession to accommodate new modes of information and support exchange taking place online is perhaps inevitable. The era of the 'e-patient' radically shifts traditional cultural models of healthcare delivery in industrialized society, challenging lingering paternalism and autocracy in the medical profession. Some respondents accepted this as a fact of life, giving up sharing information with their clinicians:

*The doctors seem to dismiss what I find out on line as unsuitable, so I don't bother now (IOB Survey Respondent 186).*

Whilst others refused to accept or bow to disapproval:

*I think my internist, who originally suspected I had CLL thinks my research is "fluff". I ignore him on this and still do it! (IOB Survey Respondent 31)*

Even in the era of the so-called expert-patient, some patients simply prefer to leave management of their disease entirely to their doctors:

*My consultant is always clear in his messages to me, and I've never read anything that I have felt I should raise with him (IOB Survey Respondent 201).*

*Some of the information is contradictory and although it seems a cop out I trust my consultant. I am on a treatment which on the internet is given as a course after a period of remission and according to the USA research is not as good as the older FCR. It is getting results for me though and I don't feel like rocking the boat (IOB Survey Respondent 199).*

*I would rather trust my doctor than anything picked up from some website I may have come across. When first diagnosed I visited the web and it scared me to death! It gave the impression that I was on death's door. That was 10 years ago and I have not used the web to help diagnose my CLL, I leave that to the professionals, Some web sites came across as ill informed and it became clear that it was hard to differentiate between the genuine and the freaky, so I do not bother looking (IOB Survey Respondent 156).*

A 2000 study showed that this was mainly the case for older, male patients, and patients in the study cited 'Wanting to be seen as a "good customer", trusting what a doctor says, and "ignorance" and the consequent (perceived) inability to assimilate medical information' among their reasons for not seeking their own information (Leydon et al., 2000:912).

Finally, concerns about general practitioner knowledge of CLL are expressed frequently in online communities, and repeated in the survey:

*The Consultant will always discuss any queries I might have. GPs are disinterested, as well as poorly informed (IOB Survey Respondent 195.)*

*only with my consultant as my gp does not give me a lot of confidence (IOB Survey Respondent 188).*

The lack of confidence in GP provision amongst patients with CLL indicates a need for further research in this area, and a need for improved communications between CLL specialists, support groups and GPs addressing the current knowledge gap and its implications for support in primary health care contexts.

## Chapter Summary

Evidently, significant numbers of people with CLL are accessing the internet for support and information. Key milestones in the disease such as diagnosis, the receipt of prognostic markers, starting treatment, and changes in rate of progression are common themes in the subject matter of community discussions. Even patients with indolent, or stable disease status maintain strong links with networks, keeping up with current treatment innovations, CLL news in general, and accessing psycho-social support systems, although a desire to minimize exposure to distressing narratives from people at more advanced disease stages was commonly expressed. In general, patients report positive impacts from their online knowledge sharing, echoing findings from co-existing general literature on online health communities. Specific to CLL networks are the tensions noted in narrative support communities resulting from the wildly heterogeneous nature and outcomes of CLL, attitudes of an older demographic to online communications and hierarchies of medical knowledge, and the rapidly evolving field of knowledge and treatment protocols in CLL. Also key are inequalities in access to CLL specialists, and the role of online information sharing for those not under specialist care. Finally, and of very real significance, is the fact that CLL is currently considered incurable, placing those living with it into a position where their foreseeable futures will be intertwined with other online actors. Strong, and long-term, links are forged and maintained.

The impact of online information seeking on patients' relationships with doctors was particularly interesting, with again a fairly positive picture emerging of a move towards more

collaborative and informed relationships in many cases. However, there is still some way to go before the traditional notion of top-down information exchange from doctor to patient in the clinical setting is universally challenged. This point was evidenced both in some of the feedback from those patients actively researching online and meeting with resistance from their doctors, and also from a group of patients themselves not wishing to challenge the status quo.

The thematically presented network mapping that follows is intended to be read in relation to the voices replicated in this chapter, and readers will encounter more of them as the work proceeds. It is all too easy to make assumptions from field observations about why people do what they do online, and what they might get out of it. Simply observing online community narrative exchange could lead to a conclusion that a high percentage of CLL patients are active actors in the networks, benefitting from their interactions. The survey allows for nuancing those assumptions through thick description from respondents, some of whom don't actively participate in the networks in ways that can be captured by field observation, and illuminates areas left in the shade by online field observation alone.

It is important to remember, however, that many patients with CLL may *never* engage with online resources. At a recent CLL support meeting in Cambridge in the UK, as a member of a panel discussing patient advocacy, I asked the 120 strong audience to indicate if they used online resources to research CLL or stay connected with others by a show of hands. A significant number of the audience did not raise their hands. Although motivated and engaged enough with their disease to travel to attend a regional support meeting, voices such as these remain

outwith the research I have carried out here. It is not possible to hazard a guess at the numbers of people with CLL who neither engage with face-to-face or online support resources, and this would make for useful further research perhaps conducted through local haematology centres. Non-engagement with online resources may well be a matter of choice, but the CLL demographic are not digital natives and, as the following survey respondents show, people aren't necessarily aware enough of the resources that exist online to make an informed choice about engagement:

*I was not aware of any such websites (IOB Survey Respondent 226).*

*I didn't know about any of the other sites! This has already inspired me to start searching... (IOB Survey Respondent 201)*

Of course, the survey itself is to some extent self-selecting as it was distributed online with the aim of enriching the network information for this study gained through fieldwork rather than establishing a broader picture of engagement with online resources amongst CLL patients<sup>45</sup>. It should be read both as an active network in its own right, and an important tool for making visible some of the enactments of online practices both mapped in further detail and absent from the themed network mapping that follows.

<sup>45</sup> The responses certainly reveal useful information about online practices and attitudes among this group that could usefully be extrapolated to support further work exploring inclusivity measures for an older patient group to engage with digital communities and resources.

## Chapter 3: Diagnosis

### Introduction

Diagnosis with CLL is a devastating experience for most. Learning that one has an incurable, chronic form of leukaemia can come as a profound shock, and a lack of public and at times general medical familiarity with the disease makes it difficult to access empathetic support. As the survey work in the previous chapter demonstrates, CLL patients are actively accessing and creating online resources in varying ways to help them to live with their disease. For most, this engagement begins shortly after diagnosis, and often in response to a perceived lack of clinical information:

*My initial reaction was of complete shock which was exacerbated by the manner in which I learned of my diagnosis from my GP. In the absence of any useful information from my GP and whilst waiting for a consultant appointment I turned to the internet to learn more about CLL (IOB Survey Respondent 212).*

The shock of a cancer diagnosis for many preceded the sense that responses from clinical staff did not correlate with the extreme distress they were experiencing. This work shows that a significant number of CLL patients feel that the heterogeneous progress of CLL, and its older demographic, render it less important than more acute cancers in the minds of clinicians and the general public alike, belying the very real challenges that living (and dying) with CLL can present. Patients report feeling mis-understood, misinformed, or even 'fraudulent' in a culture more attuned to acute cancers. The mismatch between the catastrophic effect that diagnosis



had on many CLL patients, and the casual or uninformative clinical manner attitude with which they felt the news was delivered by doctors emerges as a very strong theme indeed in this chapter.

Those newly diagnosed with CLL often face a profoundly counter-intuitive situation. Diagnosed with chronic, incurable leukaemia, yet obliged to wait until symptoms become acute before commencing treatment, patients must learn to manage the cognitive dissonance inherent in accommodating rather than treating an insidious cancer in a culture strongly wedded to proactive battle metaphors in relation to cancer. Occupying an indeterminate grey zone between health and grave illness, immune-compromised, and often having little certainty about the future, the newly diagnosed and their families can struggle to make sense of their situations. Seeking knowledge, information, and social support online were key strategies adopted to manage the sense of fear and dislocation often experienced in the early days of diagnosis:

*I started researching online immediately and felt frustrated that my hematologist said prognostic testing was expensive, not useful and who would want to know anyway. CLL Topics and CLL Forum were very valuable as they brought to my attention detailed information about the disease. It took me a year to emotionally come to terms with the fact I had a terminal cancer with no idea on how long I had to live - very difficult to know what to do about life and business plans... (IOB Survey Respondent 15)*

Several key sites emerge from fieldwork, attracting frequent mentions amongst the respondents in their descriptions of the diagnostic experience. Especially popular are: Chaya Venkat's CLL Topics; Andrew Schorr's Patient Power site; the blogs of Brian Koffman, Sharman,

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and Terry Hamblin; CLLSA UK and its Health Unlocked site; ACOR's CLL listserv; CLL Canada; the Yahoo CLL sites and Macmillan.

Between them, 165 survey respondents wrote around 10,000 words of text about their diagnostic experiences, from which a number of key themes emerged. Although in a significant minority, some patients reported that online information seeking around diagnosis made them feel worse as they often encountered upsetting patient stories or survival figures that undermined their own sense of hope for the future:

*...After the initial shock I did use the internet but this did little to help me, only to frighten me more... (IOB Survey Respondent 200)*

Most though reported that the internet had ultimately helped them to find information and support in the confusing and often terrifying early days of diagnosis:

*For me, knowledge is key. I can live with any diagnosis if I understand what the illness is, how it is likely to progress, what the prognosis is and how it will be managed. I obtained a comfortable understanding by a lot of online research (IOB Survey Respondent 128).*

This seemed to be the case even where early research was a difficult and overwhelming experience:

*When I was first diagnosed, I found information on the internet somewhat overwhelming. However, I became better informed about the disease through sites like CLL topics. Today, I find Andrew Schorr's site, Patient Power, provides thorough*

*information, especially about the latest research (IOB Survey Respondent 120).*

A good deal of literature exists on patient responses to a diagnosis with both acute cancers and chronic illnesses. CLL resolutely blurs the boundaries between both, and in this chapter's perspectives I draw on studies from both fields in the recognition of a deficit of work on the impact of a chronic cancer diagnosis. Emphasis is placed on information seeking practices in cancer patients generally, notions of biographical disruption in the chronically ill, and the role of illness narratives (Frank, 1997; Kleinman, 1989; Hunsaker-Hawkins, 1999; Jurecic, 2012) in a digital era (McLellan, 1997). How do contemporary CLL patients mobilize their own stories of diagnosis in relation to a *range* of multi-perspectival narratives online to help manage the crisis of transition following diagnosis?

For the translations in this chapter, I will explore three circulating narratives in the networks: a physician patient blog addressing CLL's contentious title of the 'good cancer'; a research paper by a CLL expert and two health researchers evaluating the psychosocial difficulties of living with a disease that is 'Invisible, Incurable and Inconclusive'; and excerpts from posts by a CLL patient tracing their narrative journey over several years from newly diagnosed and seeking help to accepting diagnosis and offering help to others.

## **Perspectives: A CLL Diagnosis**

CLL is a relatively slow growing B cell malignancy, treatable though currently considered incurable. According to Cancer Research UK, around 2,800<sup>46</sup> people are diagnosed with CLL every year in the UK, and SEER estimates that 14,620 people will be diagnosed with CLL in the US in 2015, with an estimated 4,650 deaths<sup>47</sup>. Despite its relative rarity, CLL is the most common type of leukaemia, accounting for around 35 out of every 100 cases of leukaemia. More prevalent in men than women, it generally affects older people, with 75% of those diagnosed with the disease aged 60 or over. Cancer Research state that currently 44% of men and 52% of women diagnosed with the disease will survive for at least 5 years after being diagnosed, although individual outlook depends on the stage of the disease at diagnosis, and treatment regimes are evolving in a way that is likely to extend expected survival time based on older traditional protocols.

Usually diagnosed from a routine blood test, early physical symptoms include recurrent infections, swollen lymph nodes, and fatigue. Microscopically, the disease presents as an abnormally high presence of immature white cells, often fragile and “smudging” on the slide as illustrated earlier in this work. Blood tests reveal elevated white blood cell and absolute lymphocyte counts with possible platelet and haemoglobin aberrations in advanced disease.

<sup>46</sup> Figures taken from <http://www.cancerresearchuk.org/cancer-help/type/ctl/treatment/statistics-and-outlook-for-chronic-lymphocytic-leukaemia> [accessed 24/07/14].

<sup>47</sup> Figures taken from <http://seer.cancer.gov/statfacts/html/clyl.html> [accessed 31/07/15].

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Lymph nodes may be enlarged, most palpably in the neck, groin and armpits, with organomegaly, or swelling of the spleen and liver in advanced disease. Traditionally, the degree of progress read through these signs is translated into two staging systems named for the CLL specialists who pioneered them: Rai (1968) and Binet (1981) and compared in Figure 12 below:

Image removed due to copyright restrictions

**Figure 12: GRIBBEN, J. (2010) Median survival times in CLL, from 'How I Treat CLL Upfront'. Blood Journal [Online] 115(2), 187–197. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2941409/> and linked to CLL page on Lymphomation site.**

Still used in clinical settings, these classifications can appear somewhat crude and generic to patients whose particular genetic status and treatment choices may now alter expected outcomes in ways not foreseen at the time.

As stated, CLL is a B-cell malignancy, and diagnosis is confirmed through immunophenotyping. Using a flow cytometer, this process reads surface molecular expressions on B cells against

standard patterns exhibited in CLL, and allows for basic prognostic readings based mainly on CD38 expression<sup>48</sup>. Currently, at this stage, CLL patients will be either placed on a “watch and wait” regime involving regular monitoring by their haematology consultant or GP, or given further prognostic testing if disease progress or differential diagnosis is evident<sup>49</sup>.

## **Perspectives: Diagnostic Miscommunication (Where CLL Worlds Collide)**

The above section lays out clinical frameworks for a diagnosis with CLL. Fieldwork in this project demonstrates a shared sense among significant numbers of CLL patients that shows that their diagnosis could have been communicated more effectively by their clinicians. Many patients feel that the subjective experience of having a chronic, incurable cancer isn't matched by the often casual manner of its diagnostic and ongoing clinical communication, or by the broader socio-cultural attitudes that such clinical attitudes to some extent shape. Furthermore, where patients have already taken to the internet to research their own disease on diagnosis, resulting awareness of the complexity and potential seriousness of their condition may *compound* a sense of having been inadequately informed and poorly supported by doctors who downplay a CLL diagnosis. This section explores tensions between subjective, biomedical and social experience of illness generally in existing literature, in the context of previous research on

<sup>48</sup> CD38 is a surface protein, the presence of which is thought to be associated with a poorer prognosis in CLL, and is identifiable by flow cytometry. For an in depth discussion, See Del Poeta, G. Et al's paper, 'Clinical significance of CD38 expression in chronic lymphocytic leukemia' published in *Blood Journal* (2001).

<sup>49</sup> CLL and small lymphocytic lymphoma (SLL) are different manifestations of the same disease; SLL is diagnosed when the disease is mainly nodal, and CLL is diagnosed when the disease is seen in the blood and bone marrow. Mantle cell lymphoma can have a clinical presentation very similar to that of CLL, but it is more aggressive. See Mir, M. et al (2015) for a full exploration of differential diagnoses in CLL.

quality of life for CLL patients specifically, and survey responses from my own work.

Diagnosis translates symptoms to a disease, subjecting the diagnosed to a range of institutional and cultural enactments in its name. The life-world of the newly diagnosed is altered by the subjective experience of illness, and they may be redefined socio-legally as 'sick' formulating a new identity and an identity crisis<sup>50</sup>. Distinct biochemical, subjective, and social dimensions to understanding the various spheres in which ill-health operates are identified in the following triadic approach, and are useful for exploring the dissonance between the subjective illness experiences experienced by many CLL patients, and the clinical/social responses evoked:

- Disease is a negative bodily occurrence as conceived of by the medical profession.
  - Illness is a negative bodily occurrence as conceived of by the person himself.
  - Correspondingly, sickness is a negative bodily occurrence as conceived of by society and/or its institutions.
- (Hoffman, 2002, cited in Da Rocha and Etxeberria, 2013: 61).

For most people a diagnosis of leukaemia in relation to the often relatively mild (or non-existent) symptoms experienced in early CLL comes as a complete shock:

*The shock of being diagnosed with CLL after a routine blood test was difficult. Only now after 16 months and just starting treatment can I say the words "cancer" and "leukaemia" without feeling upset. I have found the Macmillan information on the internet and booklet... ( IOB Survey*

<sup>50</sup> Talcott Parsons (1978 [1951]) was highly influential in defining the notion of a 'sick role' within the sociology of health and illness in the 1950s/60s, and its implications for doctor-patient relations. Parsons argues that the physical disability of serious illness creates a dependency in the afflicted which deviates from the expected social roles. Conforming to the expectations of a 'sick role' however, legitimates such deviancy and obviates the sick person from guilt or blame within specific parameters of behavior. See Lupton (2012: 4) for an expanded view of Parsons' 'sick role'.

Respondent 190).

Often in the early stages of CLL, the patient's perception of being 'ill' doesn't correlate effectively with their broader cultural understanding of what it means to have leukaemia – a word so culturally loaded that the above respondent takes 16 months to be able to use it in relation to themselves without distress. The twin exclamation marks following the following response similarly indicate the disparity between the gravity of the diagnosis and the subjective experience of illness experienced in early or indolent CLL:

*My first reaction was - I don't feel ill!!!* (IOB Survey Respondent 251)

CLL patients soon learn however that they are (and will remain) significantly immune compromised and vulnerable to serious infection and phases of debilitating fatigue, yet can often feel (and look) quite well. Being defined as a 'cancer' patient, whilst not obviously satisfying cultural expectations of this most feared of diseases produces further tensions for patients. Furthermore, CLL defies universal recognition as a singular disease by shape-shifting from indolent to aggressive, from relatively benign chronic disease to acute killer, and even in its progressive manifestations may include fairly lengthy periods of watchful waiting with very few outward manifestations of disease. Attitudes from those without CLL, clinicians included, inevitably reflect its ambiguous nature, and can leave CLL patients feeling confused and unsupported.



Among IOB survey respondents, dissatisfaction with diagnostic communication related both to the attitude and circumstances of diagnosis and in the amount of information and support offered:

*My diagnosis was a shock and the doctor was pretty diabolical, insensitive and unhelpful so the Internet has provided information and support beyond what I could imagine. I found a Facebook group - this continues to be my main resource now that I have done extensive research it's just nice to have people to share thoughts with (IOB Survey Respondent 232).*

*Diag 2003 age 44 . I feel it was badly handled by a dismissive GP, and Consultant. Consultant was already holding the door open for me to leave his office as he answered my question 'Is it curable?' (IOB Survey Respondent 148)*

*My GP at that time gave misleading info and was very off hand. He told me via the 'phone with little time for me (IOB Survey Respondent 150).*

*I am still coming to terms with having been diagnosed with CLL. My GP was so 'matter of fact' when informing me. I have gained more information from the CLL site than from my GP (IOB Survey Respondent 253).*

'Diabolical', 'insensitive', 'unhelpful', 'dismissive', 'misleading', 'off-hand', 'matter of fact', the language used by this small selection of a much larger group of respondents making similar observations reads like a litany of insensitivity at best, and a lack of professionalism at worst. So why do so many patients feel their experience of CLL is grossly misunderstood? The relative paucity of quality of life studies in CLL alongside lower symptom levels in early stage disease, and the generally better prognosis of CLL than some acute cancers may lead to an under-

appreciation of the psychological challenges faced by CLL patients, and a subsequent lack of 'effective interventions to address their needs' (Shanafelt et al., 2007:262).

Aside from its incurability, heterogeneity, and the current limitations of accurate prognostication (or access to it), access to expensive new molecular treatments remain inconsistent meaning that, despite excitement surrounding improved treatment protocols, for many contemporary CLL patients, chemoimmunotherapy (CIT) remains a sole option. Network responses to issues surrounding prognosis and treatment will be explored in the coming chapters. Although coming to terms with a cancer diagnosis for which most patients will be told there is no immediate treatment is a challenge, this work has shown that most patients soon accept that the toxic, diminishing returns of repeated CIT cycles means that *not* being treated early is preferable in reality. However, the psychological balancing act required to manage the impact of living with an insidiously progressing systemic cancer against the need to manage toxicity<sup>51</sup> through CIT can take a tremendous toll on CLL patients. To co-exist comfortably with a potentially fatal cancer in this way would be unimaginable to most people, yet the ability to do so and to get on with life with very little recognition of the devastating emotional impact this can have is clearly assumed by many CLL clinicians:

<sup>51</sup> Secondary myelodysplasia (MDS) and acute myeloid leukemia (AML) are frequent long term complications in Chronic Lymphocytic Leukemia (CLL) patients with around 10% of NHL (non-Hodgkins Lymphoma) patients developing these potentially devastating complaints within 10years of CIT. Although disease-related immune-suppression plays a crucial role in this process, there is concern that therapy further may further increase the risk. See Ricci, F. et al (2011) in their paper 'Therapy-Related Myeloid Neoplasms in Chronic Lymphocytic Leukemia and Waldenstrom's Macroglobulinemia' for further discussion.

In an era where 70-80% of patients with CLL are diagnosed with early stage disease, the failure to recognize and address the emotional impact of CLL on early stage patients could lead to substantial and possibly preventable distress (Shanafelt et al., 2007:262).

In her online feature 'Doc, How Long do I Have?', key network actor Chaya Venkat (whose site CLL Topics features as a translation in the next chapter) draws on Hollywood representations of acute cancer diagnosis to illuminate the dissonance between its dramatic cultural coding, and the reality of being diagnosed with a chronic incurable cancer:

Given that CLL is supposed to be the "good" cancer, it is much more likely that instead of corny pathos and empathy you will get flip condescension and told not to worry your pretty little head about it, go home and not bother the nice doctor... (Venkat, 2012)

Whilst acute leukaemias and lymphomas occupy an almost dis-proportionate space in popular cultural images of cancer, chronic leukaemias are diseases with almost no popular cultural resonances, being rarely depicted in the media<sup>52</sup>. Neither located as (preferably young) tragic victim, visibly dying from an incurable cancer, or brave warrior, visibly fighting for one's life within the compressed narrative time frames of acute illness, the CLL patient occupies a narrative hinterland. The sense of 'underwhelment' often accompanying conveyance of a CLL diagnosis is not limited to the clinical sphere. The response of friends and family to a recently diagnosed CLL patient failing resolutely to display obvious cancer signifiers can include

<sup>52</sup> In an analysis of 40 Hollywood produced films portraying cancer from 1935 until the mid-nineties, 19 portrayed main protagonists suffering from leukemia or lymphoma. A similar dis-proportionate representation of patients under 30 years of age (50%) and under 40 years of age (75%) was noted. Author Robert Clark hypothesizes that "In order for films to continue to depict "clean" cancers, in young, attractive subjects, leukemia/lymphoma has become the modern movie cancer (Clark, 1999)

confusion, scepticism or outright disbelief<sup>53</sup>.

Accurate diagnostic information is about much more than facilitating emotional adjustment. A cancer diagnosis can have a profound impact on expected lifespan, and information about how that is at least *likely* to play out will be a part of adjusting future plans and major life decisions accordingly. Consider the devastating impact of underplaying the potential of a CLL diagnosis on the following respondent, the partner of a CLL patient who was dead five years after being diagnosed with the ‘good cancer’:

*Truly would have lived those last 5 years of his life totally different because we could have managed financially but I kept working for health insurance reasons. Big mistake but we had been told this was the "good" cancer and he would likely live to die of something else. Wrong (IOB Survey Respondent 40).*

In terms of the triadic model set out at the start of this section, the subjective (illness) experience of the patient can be read against the biomedical (disease) practices of the clinical team, and how the latter ultimately defines the socio-legal practices of institutions required to provide benefits, insurance and so on should the patient require them (sickness). Network discussions reveal that CLL patients often experience real difficulties with these overlapping spheres. Once diagnosed, a CLL patient may, find themselves categorized as a ‘terminal’ patient for insurance purposes, be unable to obtain life or travel insurance, and face problems with

<sup>53</sup> Several stories were encountered in the networks during the period of research outlining incidences of friends, family members, colleagues and employers casting doubt on the validity of a CLL diagnosis amongst those patients in watch and wait and with no visible outer signs of disease. For ethical reasons concerning privacy and consent, they cannot be replicated here.

equality in the workplace (some IOB survey and network respondents reporting losing their jobs soon after diagnosis due to absence or requirements for necessary adjustments). The same patients however report difficulties in accessing benefits, qualifying for medical or early retirement, or claiming their critical illness cover on existing life insurance policies. It seems that the social status of the CLL patient as 'sick' is as mutable within the various economies it impacts on as is its status within the broader hierarchies of disease according to medical professionals. While the subjective experience of illness with CLL itself operates on a wide continuum, contradictions in definition and practices in relation to this disease broadly remain significant, having a deleterious material effect on many patients' lives.

A posting selected from physician/patient Brian Koffman's blog in the network Translation that follows allows us to consider the contexts that might underpin tensions between subjective and biomedical enactments of receiving and delivering a CLL diagnosis in the clinical setting.

## Translation: Living With the 'Good Cancer' (A Physician/Patient Blogs)

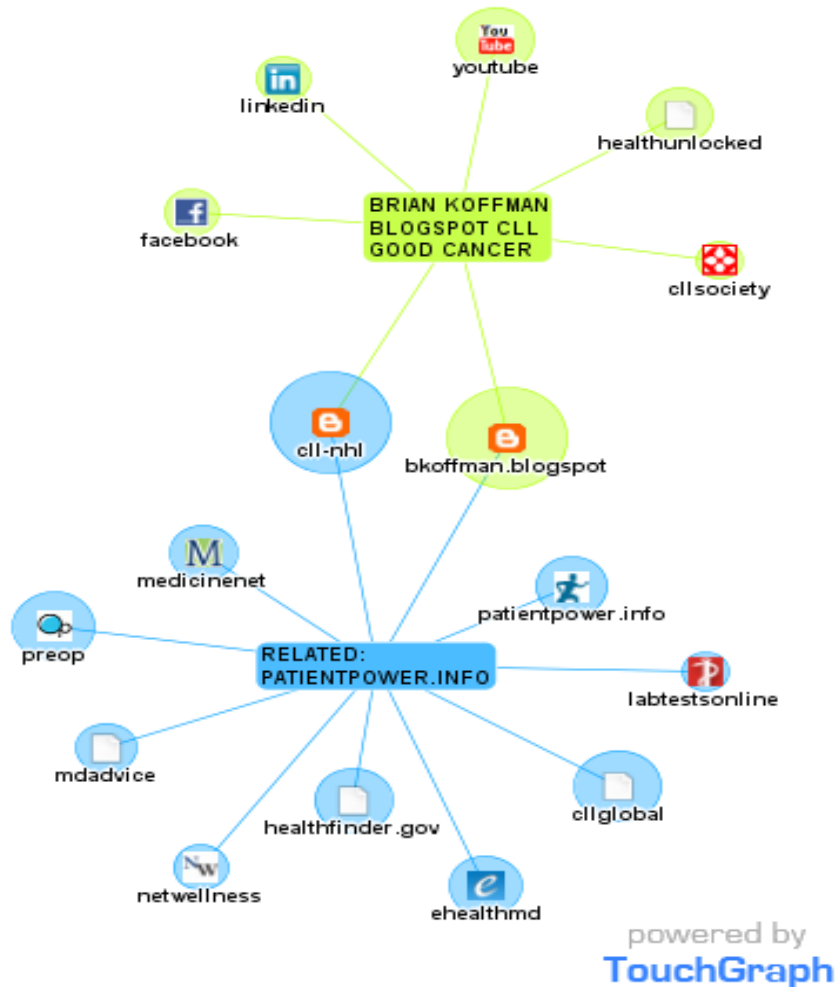


Figure 13: TOUCHGRAPH (2015) network connections from Brian Koffman's Blog to Andrew Schorr's advocacy Site, Patient Power [Network Map]. [Online] Available at: <http://www.touchgraph.com/seo/launch?q=brian%20koffman%20blogspot%20patient%20power> [Accessed 25/07/2015].

In the current absence of dedicated research among clinicians diagnosing CLL, speculative explanations for poor diagnostic communication experiences might include commonplace delivery of initial diagnosis by general practitioners; inconsistencies in cutting edge clinical

knowledge about the disease outside of a specialist setting; and its generalized status as a 'chronic' cancer usually diagnosed in older patients, which may make it appear less immediately important to clinicians<sup>54</sup>. This Translation takes a closer look at clinical enactments of diagnostic communication in online narratives, and considers how such practices might be enhanced through strategic networked narrative circulation.

Many CLL patients will, at some point, be told that we are lucky to have the 'good' cancer – an unacceptable oxymoron for many, despite its intentions to convey the relative preferability of a CLL diagnosis over a more aggressive cancer. Clinical use of comparative outcomes between acute and chronic cancers as a frame in diagnostic communication is explained, and to some extent supported (if the manner in which it is often communicated is not), by Brian Koffman in a posting about the so-called 'good cancer' issue on his blog 'Learning from and about cancer (chronic lymphocytic leukaemia or CLL) in 2014: A US family doctor, Koffman was diagnosed with CLL in 2005. Narrative accounts of doctors become patients are well documented (Klitzman, 2007; Jones, 2005; Campbell, 2012; Granger, 2014; Tomlinson, 2014), at the same time illuminating the presence and indicating the potential porosity of the normative hierarchies underpinning clinical and patient roles in everyday practice. Catapulted by illness

<sup>54</sup> In ICM research 48% surveyed believed stereotypes and assumptions about the elderly held by health professionals contributes to the UK having some of the worst cancer survival rates in Europe for older people. These findings are echoed in recent reports published by the Royal College of Surgeons (2012) and the Department of Health (2012) evidencing that some health professionals make age-based assumptions about people's ability to tolerate cancer treatment. See Macmillan.org news feature 'Ageism in NHS stopping older cancer patients getting treatment', 20/12/2012.

<sup>55</sup> See Tomlinson (2014) 'When doctors become patients', an entry posted on January 27, 2014 on Jonathon Tomlinson's blog 'A Better NHS' for an excellent explication and literature review of the phenomenon and impacts of doctors experiences of patienthood.

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into the role of patient, yet imbued with the professional knowledge and expertise of the trained clinician, such doctor/patients experience disease from a unique perspective<sup>55</sup>. Able to speak as a patient with the considerable clinical skills and insights gained from his professional experience, it is unsurprising then that Brian Koffman's blog is hugely popular resource in the CLL networks. Koffman himself is a key actor in CLL networks online, attending major haematological conferences, producing video interviews with CLL experts which he disseminates via his blog to several of the major CLL forums, and contributing to debate across the networks. He describes the aims of the blog thus:

WHAT STARTED AS A PERSONAL JOURNEY MORPHED INTO A WAY TO SHARE WHAT'S UNIVERSAL IN DEALING WITH CANCER, IN MY CASE A NASTY LEUKEMIA (CLL), A FAILED TRANSPLANT AND SUCCESSFUL EXPERIMENTAL THERAPY. THE TELLING OF MY JOURNEY HAS BECOME A JOURNEY. IF YOU SHARE A NEED TO LAUGH AND TO KNOW AND AN UNWILLINGNESS TO ACCEPT THE IMPOSSIBLE, PLEASE FOLLOW ALONG. THIS BLOG IS HERE TO TEACH ON CLL AND BLOOD CONDITIONS AND CANCERS IN GENERAL. AFTER ALL, WE ARE ALL IN THIS TOGETHER (<http://bkoffman.blogspot.com>).

On March 14th, 2014, the blog entry was entitled 'The Good Cancer', and was prefaced with the following statement:

Here is a post I wrote in response to a spirited discussion in a CLL forum on the topic of how we patients are informed about our diagnosis and the unnecessary anguish called by sometimes well-meaning but poorly informed and of touch physicians. As is everything in CLL, it's complicated and clear and sensitive doctor-patient communication is the starting point for a good outcome (Koffman, 2014).



From his vantage point of physician/CLL patient, Koffman introduces his blog post as a means of exploring doctor/patient communications in CLL. We learn that this post has already been circulated in the networks as a contribution to a forum discussion concerning the problem of poor and distressing diagnostic communication. Re-posting by the author across major network nodes in this way demonstrates how network narrative flow can be facilitated by key actors such as Brian Koffman, galvanizing debate on important themes across the wider CLL community online.

Opening with the observation that ‘CLL is too often still called the "good cancer" and all of us CLL patients rightfully hate that’, Koffman initially locates himself in the narrative as a patient. He acknowledges the cultural loading of the word ‘cancer’ itself, arguing that it is not the word ‘good’ that upsets patients, but the fact that it precedes the word cancer in a conceptually impossible coupling. “Cancer is such a loaded and malevolent word that the idea of putting something positive in front of it carries a similar horror and disbelief that would accompany anyone uttering a phrase such as: it was only a ‘gentle’ abuse” (*ibid*). But Koffman is a doctor too and, although by no means excusing what he defines as “poor doctor-patient communication”, in his clinical role he is able to identify potential institutional and professional barriers to effective diagnostic communication such as limited consultation time, and inconsistencies in medical literacy amongst patients: Many patients don't know what indolent means until well after they have been diagnosed, and to say slow growing, many patients might only hear the "growing" part especially when it is qualified with the adverb, "usually"(*ibid*).

Comparing the improving future outlook, and the slower progress of CLL to more aggressive cancers, Koffman positions the CLL reader as relatively privileged in comparison to those facing more aggressive cancers, directly appealing to them to try adopting the role of both patient *and* physician in imagining which diagnosis they would receive or give:

Ask most patients with pancreatic cancer or MDS or glioblastoma multiforme or metastatic ovarian cancer if they would want to trade their cancer for ours. Ask any doctor which bad news he'd prefer to share with his patient (*ibid*).

Expressing the belief that it is a health care worker's responsibility to comfort through communicating hope "where hope is a real possibility" (*ibid*), Koffman acknowledges that this is a very hard balance to achieve in communicating a CLL diagnosis. Locating himself "as both a doctor and patient" (*ibid*) in the debate, he asks readers to consider the following delivery of a CLL diagnosis as an alternative to being told they have "a good cancer":

You have CLL, a chronic form of a blood cancer. (Pause) While all cancer is bad, some are much worse than others. Now I want you to listen carefully to what I am about to say. (Another pause) While no-one knows the future, CLL is most often, not always, but most often, one of the least aggressive kinds of leukemia (*ibid*).

Koffman's hypothetical approach acknowledges that, whilst 'all cancer is 'bad', there are degrees of severity on that continuum. By replacing 'good' with 'least aggressive', and prefacing it with 'not always, but most often', Koffman explicitly uses comparative (worse) cancer experiences to convey a degree of comfort or hope in what is still clearly understood as a devastating diagnosis for the patient. It also acknowledges the very real possibility that, whilst it remains a likely scenario for many, the patient's experience will not *necessarily* be one of living

with a slow-growing and manageable cancer. This approach is similar to the one my own Consultant took, although he preceded his explanation by checking what, if anything, I already knew about CLL. This is vitally important. Koffman raises the issue of medical language and literacy as a potential block to effective diagnostic communication, but I would add that that can work both ways. As well as acknowledging that some patients may struggle with medical terminology, clinicians should consider the possibility that patients may already be well-informed about their diagnosis, possess high levels of medical literacy enabling them to assimilate complex medical information, or be capable of leaving the clinic and conducting effective research into their diagnosis that will render over-simplistic or euphemistic explanations redundant and a potential source for mistrust in the clinical relationship.

Locating this issue within the broader professional contexts of medical ethics and patient communication, Koffman acknowledges the difficulty faced by both physicians and patients in getting this right, pointing out that “These and similar and usually much easier issues are what I struggled with every day as a doctor turned patient” (*ibid*). Without actually supporting a shorthand descriptor of CLL as a “good cancer”, and offering an alternative possibility, he positions readers to contemplate the clinical enactments of CLL that might underpin the approach they find so unacceptable. By circulating this as a blog entry and support forum posting, he offers it as a dialogic gesture to other CLL patients and professionals reading in the networks. The issue of diagnostic communication is articulated as a professional, ethical and subjective issue by someone who has experienced it both as patient and clinician. It is presented not simply as a closed narrative of abstraction and explanation, but instead as an

ongoing struggle grounded in existing systems of knowledge, communication, experience and practice up for debate and consideration in CLL networks online. Unusually, Koffman signs off this blog post using his medical qualifications that, as he points out, "I don't usually do" (*ibid*). In establishing authorship explicitly in his professional role, he adds legitimacy to his observations as one who has not only received a diagnosis as a CLL patient, but works with and understands the clinical contexts within which diagnostic communication operates. The patients in the audience will understand this, as will fellow clinicians.

I first encountered this blog entry on the membership only CLL Facebook page Bad to the Bone, where the following response from a CLL patient caught my eye:

I didn't even get a good cancer or bad cancer from my doctor. I had to call for my BMB results at lunch time and got his nurse who said, "Oh, yea, your results are in. You have CLL. Gotta go! I have a patient." I managed to keep her on the phone long enough for her to tell me what CLL stood for, then she hung up. I went back to my classroom and googled CLL. Everything said I'd be dead in five years. I have been with friends when they got very bad news about their cancer, and have dealt with being told that I had breast cancer. In every other case the doctors were caring, compassionate, and informative. Why is it that doctors feel that it is in any way appropriate to tell a new patient that they have "the good cancer"? I know that my strong opinion about this is colored by the fact that I have just lost two friends to this "good cancer" and a third is fighting for her life, but I find the expression "good cancer" to be totally unacceptable! ('Bad to the Bone' group member Facebook, 11<sup>th</sup> March 2014).

Clearly unimpressed with the off-hand manner in which her own diagnosis was conveyed, this group member effectively articulates her feelings about the misnomer of 'good cancer' in relation to a disease which has already killed two of her friends, and has another fighting for her life. The posting powerfully expresses the perceived flippancy with which many

respondents felt their diagnosis was conveyed, and its inadequacy in the face of actual outcomes for many CLL patients. Those actually subjected to the 'good cancer' routine by clinicians express similar anger and cynicism about their doctor's communication skills and knowledge when their own and fellow online patients' experiences soon prove otherwise:

*Used the internet for info as GP didn't know much - was told it was 'good' but it progressed within 6 months - lost job immediately (IOB Survey Respondent 9).*

*At first I was shocked, then angry because the doctor kept referring to it as the "good cancer". It infuriates me that ANY doctor can think of ANY cancer as a good one (IOB Survey Respondent 78).*

If doctors believe that simply telling a patient they have a 'good' cancer alleviates some of the burden of a CLL diagnosis, the comments encountered in Koffman's blog, its responses, and across CLL networks online generally, indicate that they are clearly mistaken.

Brian Koffman's blog functions as a valuable narrative object in the networks, allowing readers to engage with a fellow patient who can legitimately make visible the professional and institutional practices underpinning CLL care. Koffman's dual status as a CLL patient and physician enables him to map out some of the broader institutional connections that might hold what would seem to be a fairly widespread poor experience of diagnostic information and support for CLL patients in place. Importantly, he offers alternative approaches that consider professional enactments of CLL in relation to the patient experiences reported. This has the potential to transform clinical enactments of diagnostic communication, although this work

shows that respondents to discussions like this in online CLL networks are predominately patients. If more clinicians were to engage with the CLL networks then the narratives of distress conveyed by many CLL patients in response to diagnostic communication in the clinical setting might potentially exert some effect on clinical practices of communicating a CLL diagnosis, and I return in conclusion to ways in which the narrative knowledge circulating in online CLL networks might effectively be mediated into everyday clinical practice through strategic network activity.

### **Perspectives: Filling the Void (Information Seeking in CLL Patients Online)**

As demonstrated, dissatisfaction with clinical communication and information provision on diagnosis was widespread among IOB survey and network respondents, and turning to the internet to bolster support and information was reported as a common strategic response:

*Initial diagnosis was a shock. Very little support or advice was given by my local hospital and I had to revert to the Internet for answers. My local hospital was, to be frank, dismissive of questions asked. I reverted to the internet and finally found a support group CLLSA who gave me answers. I then used internet to find a consultant who was extremely supportive and gave me answers to question... Since being under his care the fear has gone, I regularly get support if needed (IOB Survey Respondent 237).*

This respondent outlines his process of online information seeking in response to inadequate advice and support on diagnosis, leading ultimately to locating a supportive consultant. Using online networks to pro-actively manage access to satisfactory care in this way demonstrates just how

effective digital support and information seeking can be for patients. This contextual section looks at the information-seeking behavior of CLL patients in relation to that of cancer patients generally in the first section, explores the potential of online information seeking as a tool for adjustment to diagnosis in the second section and, in the final section, considers the impact of information seeking and lay expertise on the traditional hierarchies of medical knowledge exchange.

### **Information Seeking on Diagnosis: Turning to the Networks**

Whilst low emotional well-being scores recorded by CLL patients (Shanafelt et al., 2009a) indicate that this is a group with special needs in terms of diagnosis, *any* diagnosis with cancer is likely to challenge both clinicians and patients in a number of ways. Patients reflecting on receiving a cancer diagnosis in a 2001 study reported focusing on three key elements: (1) content (what and how much information is told); (2) facilitation (setting and context variables); and (3) support (emotional support during the interaction) (Parker et al., 2001:2049).

As this work shows, many CLL patients don't fare especially well in any of the above areas on diagnosis, some reporting receiving the news by telephone, others having it conveyed by empathetic yet uninformed GPs, and others by seemingly unconcerned or overly casual practitioners in specialist clinics, yet the literature demonstrates hopefulness in cancer patients to be enhanced where clinicians demonstrate expertise and offer up to date information:

Patients indicated that the physician's expertise and being given information on their condition and treatment options were areas of greatest importance to them... Sardell and Trierweiler [also] found that the behaviors that patients rated highest in enhancing hopefulness were those related to the technical and informational aspects of the communication (eg, physician offers most up-to-date treatments available) (Parker et al., 2001:2054).

Considering CLL patients already experience lower emotional well-being following diagnosis than other cancer patients (Shanafelt et al, 2008), and that they frequently report poor diagnostic communication and support and inconsistency in disease-specific expertise of diagnostic clinicians, it is not difficult to see why so many CLL patients rely so heavily on other sources to learn about their disease. After receiving what they perceived as their 'death sentence' from an unforthcoming consultant, the following respondent turned instead to the (now closed) Bristol Cancer Centre in the UK for support:

*I was diagnosed 10years ago. I asked the consultant what the prognosis was and her only words were 'ten years'. I then asked if there was 'owt I could do. This elicited the total response 'no'. So much for the famed progress in treating the whole person in medical training. I was so shocked by the diagnosis that I had nothing else to say - I'd had my death sentence and that was it, like Scrooge seeing his own headstone (IOB Survey Respondent 235).*

A cancer diagnosis radiates in its impact across social networks, and it is not only patients who turn to the internet following a diagnosis:

*Like most, my family and I found the diagnosis nothing short of catastrophic. My husband and parents initially used the internet and the CLL topics and CLL forum proved invaluable and to this day, are the ones I use. Having fantastic support from family and friends has been the key to coping with everything but the internet has been my main source for educating myself (IOB Survey Respondent 95).*



Those going online to fill a void of diagnostic information are inevitably exposed to the inconsistencies in approaches to treatment and care they may face, and thus the cycle of knowledge-based self-management that often leads patients to challenge or even change their doctors begins, and the potential long-term benefits on the quality of life of CLL patients is clearly demonstrated by the 83% figure of IOB survey respondents reporting that online information helped them to live with CLL. However, the short-term perils of self-motivated online research for the uninitiated are manifold, key amongst them being the dissonance between the often bleak median survival times, and stories of rapid disease progression and death amongst CLL patients encountered by newly diagnosed patients with no frame of reference:

*I do not think medical people realise the effect of being told that you have CLL has on the patient. Often the diagnosing medical person is not an expert on CLL. A lay person researching on the internet internet can perhaps pick up on the wrong info, I read a 2-5 year life expectancy out of context (IOB Survey Respondent 10).*

The level of information required by individual patients on diagnosis will of course vary. Many respondents in this work reported high levels of information seeking to help manage post-diagnostic uncertainty, but some reported that *too* much information inhibited hope. Others reported cyclical searching patterns according to various phases of their disease, and some practiced total avoidance. This stratification reflects the identification in existing work on information-seeking practices in the newly diagnosed chronically ill of three distinct approaches, from actively seeking as much information as possible (even where that proved frightening), through selective interpretation of information in line with their ability to absorb

it, to outright avoidance in an attempt to remain calm and content whilst they still could (Pinder, 1990, cited in Radley, 2004:144).

## **Transitions: From Abject Terror to Accommodation Online**

Many respondents describe an initial terror on diagnosis, and the belief that they were about to die. In the very early stage of diagnosis, online information in some cases compounded that fear, largely due to the lack of knowledge required to effectively evaluate its relevance to their own situation. However, initial panic subsides somewhat once it becomes clear that death is not necessarily imminent, and judicious use of the internet is reported as being ultimately helpful in relation to understanding that CLL is rarely an immediate killer:

*At the time of diagnosis I went through the classic stages of grief, and wanted to research all aspects of the disease this was through the internet, through a document given to me by my GP and through booklets sent through the post from CLL Support Ass. and Leukaemia Care. It was a journey that felt like a rocky road at the start, but is now a much more stable ramble along - the information gained helped me to understand the situation and put it all into context, although some data left me feeling scared and worried for my future - with hindsight I think i was just looking to see when I might die from this - now I get on and live with it and the data esp from CLLSA Healthunlocked [sic] helps me to do that (IOB Survey Respondent 185).*

This respondent reflexively acknowledges her response to diagnosis as one of loss, accompanied by the classic stages of grief. The psychosocial impact of a diagnosis with cancer is significant, as is the personal adjustment required to facilitate an act of transition from 'healthy' to 'ill'. Diagnosis is "literally the dawn of a new reality, the world of illness" (Brennan,

cited in Carel and Cooper, 2013: 136). Pertinent in the response is her shift from seeking information to ascertain when she might *die from* the disease to using it instead to help her get on and *live with* the disease. In the literature, Fredrik Svenaeus draws on Heideggerian phenomenology in interpreting diagnosis with a life threatening disease as productive of a sense of alienation from the lived body, and of a generalized “unhomelike being-in-the –world” (Svenaeus, 2011, cited in *ibid*: 135). If the ability to return to some form of homelike being-in-the world after diagnosis is to some extent dependent upon a patient’s success in adapting to the changes in and implications for their lifeworlds (*ibid*: 134), then maybe we can read Angela’s assimilation of ‘data’ gleaned from an online support facility over time as helping her transition to a world in which she can feel comfortable again.

The nature of online data in relation to CLL is broad and multi-sited as this work has and will continue to demonstrate. Describing researching CLL through ACOR (an established on line community) as ‘an adventure’ in learning, the following respondent articulates the hub-like nature of an active network node, connecting users to a whole range of narrative enactments of CLL:

*In the mid-90s when I was diagnosed with CLL, there was little printed material available. But, I found an online support group (ACOR's) which opened hundreds of doors to me, including research, support, controversies, spotting "fake stuff," medical experts, understanding prognosis, understanding genetic elements, etc. I soon was familiar with the "jargon" of CLL, and comfortably read the research and entered into dialogue with others. So the first year or two after diagnosis was not full of fear; rather, it was more of an adventure to see what I could learn (IOB Survey Respondent 17).*

Connecting multiple narrative accounts of CLL from multiple actors, online CLL networks have the potential to afford patients a degree of omniscience in relation to the various practices that bring their disease into being across biomedical, subjective, and socio-legal spheres, potentially enabling more effective transitioning. Despite this, some respondents were advised specifically NOT to use the internet:

*... I remember being told by my haematologist at diagnosis that "it's not cancer" and "don't check the internet"...I guess I blotted out how I felt at the time and it took me a few months before I could come to terms with my diagnosis and start seeking information on line. Thankfully I quickly found some reputable sites. Looking back, I can appreciate being told "not to check the internet", but being given a list of reputable sites would have been more useful! (IOB Survey respondent 4)*

*My diagnosis was in 2004 by my family doctor who told me "you have CLL, I'll refer you to a Hematologist, DON'T look on the Internet for information". I had no idea what CLL was and I worked in Health Care. Needless to say, both my Hematologist and Family doctor have been fired. It took me a while to get over the shock, find out what CLL was and get on the internet. As a result I have met a great group of CLLers and been involved in the CLL Patient Advocacy Group in Canada (IOB Survey Respondent 94).*

It might be reasonably assumed that edicts to stay away from the internet could be based on doctors' well-meaning assumptions that their patients don't have the knowledge or resources to filter information effectively. The previous chapter has demonstrated however that clinicians' resistance to their patients' online information seeking behavior can be as much about the consequent demands placed on them to contextualize findings in clinic as protecting patients from distress. Whatever the motivation, as respondent 4 insightfully points out, it would be more useful to suggest reputable sites for online support and information rather than

issuing ultimately impotent vetoes on online research altogether, as if the genie of access to information could be returned to its bottle by doctor's orders not to look.

A minority 2% overall of IOB survey respondents reported not finding the internet useful in helping them to live with CLL, citing reasons such as finding the internet too impersonal, frightening or not comfortable for 'personal issues', and expressing a preference for face to face discussions with their clinicians, and 'printed information' from recognized support organisations:

*I found my diagnosis terrifying, never having previously even heard of CLL, and I thought I was under a death sentence. After the initial shock I did use the internet but this did little to help me, only to frighten me more. Only by speaking to the consultant at the hospital was I really able to get my head around the issue. As already mentioned, I found comments by other CLL sufferers within the CLLSA forum, frightening. I received the CLL handbook in the post and another similar booklet from the hospital which is where I learnt most about the condition (IOB Survey respondent 200).*

*... I'm not a great internet user for personal issues and would much rather have printed information. I suspect quite a few people may be of a similar nature (IOB Survey respondent 231).*

*The Macmillan booklets and Macmillan nurse were very helpful - the online info was too impersonal (IOB Survey respondent 219).*

Whether this is a generational issue or simply a matter of preference for those wanting to control information exposure requires further research with this patient group.

## **Perspectives: Knowledge and Power in the Networks: The closing Expert/Lay Gap and its Paradoxes**

Having gone online to identify their symptoms following an initial diagnosis of a probable hematological malignancy, the following respondent expresses some relief at having their suspected self-diagnosis of CLL confirmed by a doctor:

*In the time between the blood results and definitive CLL diagnosis, I scoured both the internet and print sources and found that in the absence of any acute symptoms the most likely diagnosis was CLL... ..It was and I was actually rather relieved because it could have been much worse. The internet, especially the ACOR list and CLL Topics were priceless resources during this frightening time and they continue to be so seven years later. Lately I have also logged on to Patient Power ... which gives me access to the views of CLL experts around the world (IOB Survey respondent 37).*

Such responses could be read as part of a repertoire of reflexive selfhood in contemporary health consumers in line with existing work that positions the world wide web as a “self-help agora” (Orgad, cited in Gauntlett and Horsley, 2000:146). Whilst clinicians retain a vital role in validating and legitimizing diagnosis<sup>56</sup>, patients primed through self-help are arguably better prepared to ask relevant questions of their doctors:

*My GP ...finally told me she was running blood tests for CLL and advised they were starting with the worse case scenario [sic] & working backwards. A week later it was confirmed I was stage A CLL, by which time I had massively researched online so was well prepared with questions for when it was confirmed. My GP was quite upfront &*

<sup>56</sup> According to health online polls conducted by Wolterskluwerhealth.com (2015) a majority of consumers (77%) who use the internet to diagnose an illness say they follow up with a doctor to verify that diagnosis.

*honest and said her knowledge was limited* (IOB Survey respondent 211).

Pertinent here is that, having already researched her potential diagnosis, respondent 211 is more informed about CLL than the diagnosing doctor. Like my own, her GP willingly professes a limited knowledge of the disease, challenging traditional hierarchies of knowledge transfer in doctor-patient relations. This work indicates that a significant number of well-informed CLL e-patient know as much or even more than their GPs, and general haematologists, raising questions of how expert patients and doctors negotiate the subversion of traditional hierarchies. Diagnosis and first consultations represent the initial encounters of CLL patients with their medical teams, occurring at a point where patients are very often vulnerable and afraid. I have already noted work demonstrating a strong desire among cancer patients for competent and efficient clinical information on diagnosis, and the subsequent damage to trust in the clinical relationship that can occur in its absence. This work has also shown how the CLL patients surveyed commonly address the information void through judicious online research and collaborative support seeking in the networks, from which they can fairly quickly gain expert knowledge on their own disease. Yet to feel more informed than one's doctor may tip the power balance of the clinical relationship too far for comfort for some, undermining the confidence of patients ultimately dependent on clinicians' decisions about and access to prognostics and treatment, and for validation of the 'sick' role (Parsons) required to access to socio-legal benefits. After all, and as Foucault acknowledges, the medical encounter *depends* to some extent on "a differential of power and knowledge between doctor and patient" (Lupton, 1997:119).

Enhancing the clinical relationship is about so much more than patients becoming more engaged with medical knowledge. It is equally important that clinicians are *fully* engaged with the subjective reality of their patients' illness experience in a two-way exchange of shared enactments. The role of narrative circulation online in re-defining the boundaries of acceptable ways of 'doing' disease is at the core of this project, and summed up neatly by Kathleen Pontius's observations on the two-way value of the digital narratives of young people negotiating their lives with cancer when she wonders if "Perhaps by broadening the acceptable cancer narratives, young adult cancer patients will be able to influence medical and support providers to better fulfill the needs of all cancer patients" (Pontius, 2008:99).

Narrative circulation and sharing of disease experiences online is not limited to autopathographic exchanges however. Circulating academic research into quality of life for particular patient groups also means that both patients and professionals might be exposed to important findings about the impact of living with specific diseases traditionally confined to the limited audience of professional journals. A recent eponymous paper describes CLL as a disease that is "incurable, invisible, and inconclusive", concluding that CLL patients in the watch and wait phase displayed similar levels of anxiety, depression, and reduced quality of life to their counterparts undergoing active treatment. Amongst the recommendations of this important paper were suggestions for specialists to acknowledge the psychological impacts of CLL, to actively listen to patients' concerns, and to address their needs for information (Evans, Ziebland and Pettit, 2011: 1). Given the relevance of those findings to some of the comments made by CLL patients in this project, and the fact that this paper found its way into circulation in the



online CLL networks researched, the following Translation focuses on its content and network effects.

### **Translation: Invisible, Incurable, and Inconclusive (A research Paper Raises Awareness)**

Benign as it may sound, the period of monitoring CLL prior to treatment known as ‘watch and wait’ places CLL patients in an uncomfortable balancing act between an inner knowledge of latent sickness, and the outward manifestations of relative good health. For those more fortunate individuals with indolent disease, watch and wait can be a lifelong experience with no progression to aggressive disease. Even at its most benign however, CLL significantly compromises the immune system and retains the potential to mutate into more aggressive forms along its life-cycle. For these patients then, as well as those with more progressive disease, the calm state of attentive patience implicit in the term watchful waiting is entirely euphemistic:

*Watch and Wait stinks - it's more like Watch and Worry. I would say the first 6 or 7 years were awful, feeling like the guillotine was going to drop at any time. Now I don't think about it all the time, just a lot (IOB Survey Respondent 93).*

*"Watch and wait" has impacted on my future and current lifestyle plans leaving me with a sense of loss of control over what and when I do things (IOB Survey Respondent 254).*

Julia Kennedy

Although always challenging, this this can be particularly acute where information and support for this approach to care are lacking:

*Insufficient information and support offered to be able to be able to come to terms with it and live psychologically well with 'watch and wait' (IOB Survey Respondent 148).*

This translation looks at the circulation in the networks of a research paper entitled 'Incurable, invisible and inconclusive: watchful waiting for chronic lymphocytic leukaemia and implications for doctor–patient communication', written by health researchers Evans and Ziebland<sup>57</sup>, and Consultant Haematologist, Pettit<sup>58</sup>, and published in the *European Journal of Cancer Care* in January, 2012. Figure 14 below represents one click TouchGraph showing the basic links out from the paper online at the time of writing, with important connections into major network nodes CLL Topics and Health Unlocked.

<sup>57</sup> Senior qualitative researcher, and research director respectively from the Health Experiences Research Group, Department of Primary Health Care, University of Oxford.

<sup>58</sup> Professor of Haematology, and Consultant Haematologist at Royal Liverpool and Broadgreen University Hospitals NHS Trust.

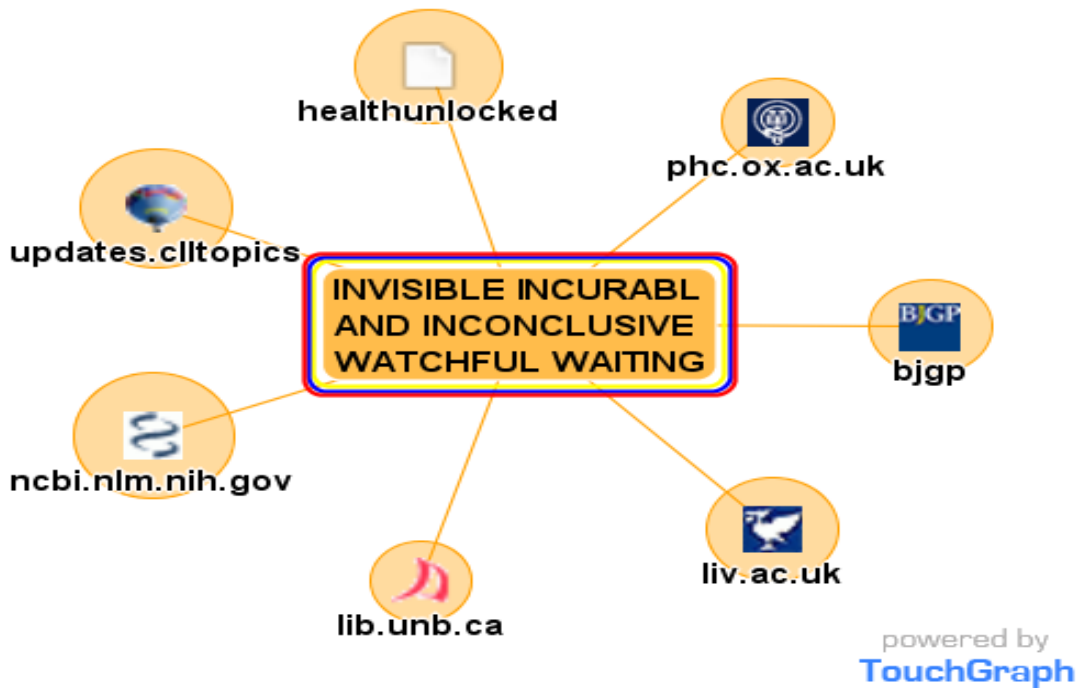


Figure 14: TOUCHGRAPH (2011) network connections from Evans et al.'s (2011) paper 'Invisible, Inconclusive and Incurable' [Network Map]. [Online] Available at: <http://www.touchgraph.com/seo/launch?q=invisible%20inconclusive%20and%20incurable> [Accessed 25/07/2015].

The research draws on qualitative interviews with twelve CLL patients managed by watchful waiting, concluding that patients on watch and wait demonstrate similar levels of depression and negative impact on their quality of life as those in treatment. The abstract states that the qualitative interviews allow the authors to relate these findings to “perceptions of the illness state, doctor–patient communication, and work pressure” (Evans et al., 2011:2). Five other key points could be extrapolated from the abstract effectively reflecting the concerns of CLL patients across the online networks about diagnosis with CLL, and living in ‘watch and wait’:

1)"Patients with chronic lymphocytic leukaemia (CLL) find it hard to accept a diagnosis of an incurable cancer for which no treatment is recommended and which may not cause symptoms for many years..."

2)"Patients with CLL recalled being given little information about the condition and wanted to know more about how it might affect them in the future."

3)"The invisibility of CLL meant that some chose not to disclose the diagnosis to others. Check-ups sometimes felt cursory, causing dissatisfaction."

4)"As symptoms increased, lifestyle adaptations became essential, well before treatment was warranted."

5)"We recommend that specialists could better support patients by acknowledging psychological impacts of CLL, actively listening to patients' concerns, and meeting their needs for information." (Evans et al., 2001:1)

The perception that not enough information or support for the specific psychological needs of CLL patients is given on diagnosis is, as this work has shown, fairly widespread across the CLL community. Again, respondent 148 describes their perception of this:

*I really think that the lack of information, lack of support, apparent lack empathy towards the emotional effects not only of the diagnosis, but also of living with fatigue/'unwellness', at the time of diagnosis, during the time since then, and also at present has resulted in a much greater negative impact on my life than might have otherwise been... (IOB Survey respondent 148).*

This respondent clearly feels that a lack of acknowledgement and support for the emotional stress of diagnosis, and physical symptoms of fatigue and malaise common to CLL has contributed significantly to a continuum of unnecessary suffering. A subsequent observation that recognition of this difficulty is 'only just emerging' evidences awareness of the current lack of research in the area of psychosocial support for CLL patients.

CLL's invisibility to the outside world means that patients often choose not to disclose their disease, and face a degree of scepticism and confusion from others if they do. In their paper, Evans and colleagues define Talcott Parsons' (1951) concept of the 'sick' role as a defined societal obligation for the sick to achieve complete recovery by eschewing normal social roles and complying with caregivers. Parsons later introduced the concept of the 'part-time' sick role (1975) to address the ongoing cycle of distinct periods of exacerbation, management, and relative good health experienced in chronic illnesses such as diabetes. The authors observe that some of their respondents questioned their status as 'ill' during the watchful waiting phase of the disease. Using Parsons' part-time sick role model allows for the argument that, even in non-progressive disease phases, CLL patients are formally in role during clinic visits and periods of unwell-ness, and thus legitimately entitled to the same degree of support that *any* sick person might expect. The authors also use the concept of 'liminality' to explore the nebulous space between illness and health inhabited by CLL patients. Neither officially ill nor actually well in the early stages of disease, CLL patients occupy a slippery and often alienating cultural territory. As Evans and colleagues go on to point out, and as the previously cited respondent testifies, the debilitating symptoms of disease progression might leave a patient feeling legitimately ill long before clinicians confer a valid sick role.

Dissonance between the lived realities of illness in CLL, and its medical recognition are core to the sense of marginalisation often reported by CLL patients during diagnosis and watch and wait as Evans et al acknowledge in their paper: "This mismatch in perceptions of the illness state could help to explain why doctors seem not to fully appreciate the impact of the illness on

patients” (Evans et al., 2011:8).

Like Brian Koffman in his ‘Good Cancer’ blog post explored in the previous translation, the authors also hypothesize that what may be read as offhand and uncaring attitudes by patients may in part at least be a result of prioritizing time and energy by haematologists working in rigidly time-constrained system:

Hard-pressed doctors working in the UK NHS understandably prioritise those patients who most need acute medical attention. In a haematology clinic, people with indolent CLL may seem to be of less interest to staff and in less need of professional care than those with acute leukaemia in hospital for lifesaving treatment. This may partly explain why some people with CLL believe that their specialists seem uninterested in their experience of the condition and do not appear to appreciate how it affects them either physically or emotionally (Evans et al., 2011:9).

Co-authored by a Consultant Haematologist specializing in CLL, and published in a specialist cancer care journal, the paper’s primary intended audience would be multidisciplinary professional readers both directly involved in caring for those with CLL or other indolent cancers, and in the implications of doctor-patient communications on patient experience. However, circulating as a narrative in CLL support networks opens up the paper’s audience to CLL patients who will recognize their own experiences reflected in the respondents’ stories, and the discussion and analysis of the findings.

The paper’s reference to a (1993) NICE recommendation that “all haematological cancer patients should have access to a specialist nurse who can offer psychosocial support and

continuity of care” (Evans et al., 2011:9) highlights institutional acknowledgement that increasing accessibility to emotional support for patients requires a multidisciplinary approach, using specialist nurses to alleviate the pressure on time for doctors. The reader is informed that there is an increasing reliance on specialist nurses for the provision of informational and emotional support for cancer patients across the board. However, this increasing reliance places nurses into the same time-pressured environment as the doctors resulting in triage based on the acute v chronic binary in which CLL is so often confined to second place:

Using specialist nurses to talk to patients about their concerns during watchful waiting can give consultants more time to deal with the more difficult cases. However, if there are too few specialist nurses to cover all watchful waiting for chronic lymphocytic leukaemia haematological cancer patients, their time is likely to be prioritised in the same way as that of consultants, restricting their use to acute patients (Evans et al., 2011: 9-10).

CLL patient readers will be familiar at least with the effects, if not the economic politics of a binary opposition between acute (“more difficult”) cases, and chronic (themselves) in which a competition for limited resources is played out. The paper’s recommendations that specialists recognize the emotional needs, and offer better support and information to CLL patients are very firmly located within a discourse of the political economy of the UK NHS. The reader is left in no doubt for example of the realities of time-management for “hard-pressed” clinicians with heavy loads of acute patients to manage. After reading about increasing reliance on the role of the specialist nurse as a key agent of patient emotional support, we learn that some of the nurses needed to spread the load of supporting patients emotionally have to be externally

funded by charities such as Macmillan.

There is no doubt however that the rich description provided by the small cohort of research respondents clearly reflects many of the key issues discussed by CLL patients online. The voices of twelve CLL patients speak volumes in this paper through the authorship of a CLL specialist clinician and two academic health researchers. The title 'Invisible, Incurable, and Inconclusive' sums up the unholy trinity of features that make CLL such a difficult disease to understand, and to live with, and the five points raised in the abstract address many of the points made by patients in my own research (and experience). To a CLL patient, the publication of this paper represents a rare oasis of specialist professional insight into the psychological difficulties of the disease. Professional recognition of these issues has the potential to legitimize the psychological distress that so many CLL patients come to internalize as a personal aberrant (inadequate) reaction to their disease, or simply endure in the absence of clinical recognition and support.

Recommendations for improved emotional support, presented predominately as a nursing rather than a medical responsibility in an environment where CLL patients must compete with more acute patients for limited resources, may do little to reinforce hope that things are likely to change radically for CLL patients any time soon. However, the fact that recognition of CLL patients' specific and unique emotional needs has been articulated and published in a professional context was seen as a positive move in the network responses to this paper.



## **Circulation**

So how does a paper like this make it into support networks, and what impact might it have on CLL patients? After its publication in the European Journal of Cancer Care in 2011, the paper appeared in the network in the following sites and formats (this is not necessarily exhaustive):

**CLL topics updates, 16th November, 2011 – précis of paper and discussion**

<http://updates.clitopics.org/4085-incurable-invisible-and-inconclusive> (56 responses)

**Lymphoma.com 16th November, 2011 – link to paper from CLL page**

‘CLL Topic Updates: “Incurable, Invisible and Inconclusive” <http://bit.ly/uo6Bad> Good discussion on having an indolent, currently incurable cancer that might also be of interest to those with follicular, malt etc.’ <http://forums.lymphoma.com/archive/index.php/t-52507.html>

**UK CLL Forum - link to article posted on 18<sup>th</sup> November, 2011 in a thread on quality of life in CLL patients**

<http://www.ukcllforum.org.uk/viewtopic.php?id=222>

**CLLSA Health Unlocked, 2012, in a posting entitled ‘You are not imagining things nor are you alone and you may not feel listened to.’**

**Macmillan CLL/SLL/HCL community 16<sup>th</sup> November, 2011 in a thread entitled ‘CLL News’ - link to paper**

**Macmillan CLL/SLL/HCL community October 2012 in a thread entitled 'how living with CLL in watch and wait feels to me' – link to paper (Hairbear)**

**Maggies online centre 18<sup>th</sup> November, 2011, in a CLL blog – link to paper (Nick)**

**Bluepeople.com, Depression and Mental Illness Forum, September, 2011 – link to paper**

**Musings of a Lymphomaniac blog in an entry entitled "living with the good cancer" 16<sup>th</sup> November, 2011**

The spread of sites is interesting as it encompasses key nodes in the CLL network, alongside a personal blog, a generic lymphoma support site, and a generic depression and mental illness forum. Also pertinent to understanding the role of key mediators in circulating information is the fact that the paper was posted to three of the above UK sites by the same CLL network actor, entitling his post to the CLLSA Health Unlocked site 'You are not imagining things nor are you alone and you may not feel listened to' and prefacing it with the quote:

If there ever was a must read paper to help explain what we may experience when living with CLL while on "watch and wait" then this is probably it. Published last year by the HERG study group at Oxford. It is a lengthy read but worth it. I know many of you have passed this onto your GPs to read. There are some interesting observations from patients and conclusions including recommendations made that are raising awareness

(Hairbear, CLLSA Health Unlocked, 2012).

That post's title itself shows empathetic recognition- that CLL patients might internalize their distress within a generalized sense of isolation redolent of the phenomenological concept of a sense of "unhomelike being-in-the-world (Svenaueus, 2011). Hairbear makes the point that the paper is 'raising awareness' of these issues. This underscores its value as a circulating narrative in the networks based on its function as a tool for drawing attention to and validating the difficulties and isolation experienced by CLL patients, for opening the issues up for debate in the forums, and for bringing those issues professionally to the attention of clinicians. The practice of patients passing the paper on to their own doctors demonstrates how narratives spill over from online networks into face-to-face encounters with the potential to influence practice in receptive clinical environments.

## **Network Responses**

CLL patients encountering this paper are positioned as readers to consider the institutional and professional enactments that frame their experiences in the clinic, recognizing their place in a competition for finite resources in an over-stretched clinical market. The political-economic discourse of the paper is not openly addressed anywhere in the network responses.

Professional recognition of CLL patients' unmet needs for emotional and informational support seems to be the dominant narrative feature driving the circulation of and responses to this paper across support networks. This perhaps demonstrates a degree of instrumentality in the

way that narratives are circulated and read according to a hierarchy of perceived relevance in the community. Responses may of course be influenced by the way the importance of paper is framed by the actor posting it. In this case, improving professional awareness of the challenges experienced by CLL patients, and the paper's narrative function in reassuring patients that they are not suffering alone are key drivers behind encouraging its flow in CLL networks.

These factors are privileged in network discussions over the institutional political-economic implications of its recommendations. The point here seems to be that, at last, there is professional recognition of a problem CLL patients struggle with almost universally, and the posting of this narrative into the networks allows for CLL patients to reflect on their own struggles as a broader problem, now validated by professional research findings, and not as something they should regard as a personal failure in coping. It is also presented as an opportunity for CLL patients to 'educate' their doctors by passing the paper on to them. Health professionals reading the paper will encounter clearly articulated narratives of the problems faced by CLL patients meshed into recognizable discourses of the institutional constraints contributing to (if not entirely explaining) failure to adequately recognize and support these problems. Once liberated from its narrow professional journal audience, and circulated among CLL patients online, this paper potentially mediates CLL across the boundaries of patient and doctor, narrativizing and validating the experiences of each to themselves and to the other. If there remains any doubt about the impact of the lack of recognition and support for patients from their clinicians that circulating this paper has the potential to change, then I return to the

words of IOB respondent 48:

*I really think that the lack of information, lack of support, apparent lack empathy towards the emotional effects ...has resulted in a much greater negative impact on my life than might have otherwise been... (IOB Survey respondent 148).*

I want to pull two themes out of this Translation to consider in relation to the literature – those of ‘liminality’ used by Evans and colleagues (Evans et al., 2012) to describe the cultural gap between illness and health within which CLL patients find themselves, and ‘biographical disruption’. In this section, I have used the term ‘biographical disruption’ to describe a life interrupted by CLL. This is just one of several approaches in the literature to conceptualizing the impact of a serious illness on a life. Its relevance to this work lies in its importance to the field of illness narratives generally, and I want to explore existing work on biographical disruption in chronic illness alongside theories of narrative re-construction as a strategy for re-imagining a life radically altered by a diagnosis. These twin perspectives provide the foundation for looking at digital illness narratives as an evolving multi-sited and networked form of the genre.

## **Perspectives: Liminality and the Narrative Hinterlands of CLL**

Evans and colleagues’ 2012 paper, ‘Invisible, Incurable and Inconclusive’, previously explored as a circulating narrative here in this chapter is a useful reference point for teasing out the peculiarities of CLL in relation to biographical narrative. The concept of ‘liminality’ employed by the authors is described as “a period and state of being between social statuses, or an

undefined status where people cannot classify themselves into culturally available categories”, and draws on anthropological work surrounding rites of passage. Victor Turner explains the liminal phase of the ritual process as one where ritual subjects’ understanding of the social was ostensibly improved by defamiliarizing and reconfiguring known cultural patterns with the intention of rupturing their “previous habits of thought, feeling, and action” and forcing them to reconsider “features of their environment they have hitherto taken for granted” (Turner, 1987: 14). (1977a). In this sense, liminality as a space occupying the interstices of cultural categorization forces us to consider the categories it *doesn’t* fit into – wellness, and illness in this case – by defamiliarizing them. It turns out that they are porous, graduated, mutable definitions. They can it seems (when you live between them) overlap, co-exist, and are by no means mutually exclusive. Unlike time-limited rituals however, the liminality experienced by the chronic cancer patient (or the HIV patient) is a lifelong experience of blurred boundaries and fuzzy definitions. Patients occupying the interstices themselves may grow to understand just how fragile and contrived the taken-for-granted constructed boundaries of the social world of illness may be, but that level of understanding doesn’t necessarily extend to the social frameworks that define and categorize disease in the worlds they will experience it in. To the doctors that diagnose and treat them, to loved ones, friends, employers, insurance agents or anyone else whose understanding of health and illness is predicated on the familiar categories we have assigned them as a culture.

CLL patients encountering this paper in the networks would understand very well the definition

of liminality:

*I am on watch and wait. The main uncertainty is how long I am going to live and a fear of getting another more serious cancer I often look up websites to find out how long people have lived with CLL... (IOB Survey Respondent 178)*

*Initially after diagnosis time seemed to shrink. I felt guilty about not being interested in looking ahead or writing a "bucket list"! Once in remission following treatment I kept waiting for the moment when I would feel "wow! it's gone!" Doesn't happen with CLL and ended up suffering from depression... (IOB Survey Respondent 175)*

Little and colleagues Little et al., (1998) identify three interdependent themes in the illness narratives of cancer patients in contemporary western cultures<sup>59</sup> that they argue together are constitutive of 'liminality'. They are worth sharing here in detail in view of their relevance to the CLL illness narrative. The first of the themes identified is what Little and colleagues refer to as "cancer patient-ness". This is characterized in the early stages of illness by the impact of the diagnosis, particularly revolving around shock, disbelief, and the confrontation with mortality. Also included here is a sense of urgency to act to manage the disease, and tensions over surrendering autonomy to medical decisions. Cancer patient-ness doesn't go away once these initial hurdles have been dealt with but remains as a persistent identification. The second, also immediate recognizable theme is defined by Little and colleagues as "communicative alienation" which refers in the early stages to the knowledge that no-one else can actually really share the abject horror of the diagnosis and treatments, and evolves into an ongoing

<sup>59</sup> The distinction is made to draw attention to the fact that industrialized Western cultures specifically have come to regard illness as an abnormal event in a life trajectory.

state of social alienation bound up in the status of being a cancer patient. Finally, the authors use the term “boundedness” to describe the limitations imposed on a patient’s “time and empowerment, ability and agency”, experienced at first as having to relinquish existing socio-economic and temporal frameworks to the demands of the medical system, and later expressed as existential constraints and deep uncertainty about the future (Little et al., cited in Roussi and Avdi, 2008:161).

Respondents with CLL express all three of the above themes in their comments and, as Roussi and Avdi demonstrate in their own work, liminality is kinetic, shifting from the shocking initial dislocation of diagnosis to an ongoing process of surviving in the interstices of cultural understandings of health and illness. As with all chronic diseases, disruption is experienced variously along the disease course from the acute phase of diagnosis to managing a life with the disease. Aside from having to take up the mantle of cancer patient-ness without access to immediate treatment, uncertainty for CLL patients is amplified by the disease’s heterogeneous outcomes, and social alienation exacerbated by immune system suppression and poor cultural understanding of chronic cancers. Progressive CLL presents patients with the long-term challenge of having to manage a liminality that ebbs (although never totally recedes) and flows from sustained to acute through the diagnosis/ progression/treatment/ remission/ progression cycle, a trajectory that may also be influenced by the unpredictable occurrence of infections,



secondary cancers, Richter's transformation<sup>60</sup>, and long term side effects of CIT.

Temporal dimensions are then both contingent on and productive of the process of living in liminality. Frank (1995) uses the term "narrative wreckage" to describe the fracturing of biographical futures (and thus by default, the biographical present that precedes them) that occur when serious illness significantly destabilizes a person's sense of future. Uncertainty about whether one should be orienting life towards the prospect of dying an earlier death through a process of gradual closure of future narratives, or towards continuing to stay alive by keeping open the narratives of future possibilities despite knowing that the disease may render them fully or partially impossible presents CLL patients with a difficult conundrum. Also living with a disease of the immune system with an ambiguous 'terminal' status, HIV-positive patients researched in the nineteen nineties expressed a similar liminal crisis.

Davies (1997) noted a number of strategies adopted by HIV patients to deal with the crushing uncertainty they faced. Broadly, they managed either by focusing on living in the present with renewed appreciation for aspects of their everyday lives, by refusing to accept present limitations on a perceived future, or by living in a backward-facing 'empty present' able to focus only on a pre-diagnosis past (Roussi and Avdi, 2008:262). It would appear that to remain in the latter state for any length of time may impact negatively on the quality of a life, whilst either of

<sup>60</sup> Richter's Transformation describes a shift from CLL to a more aggressive and difficult to manage form of b-cell lymphoma experienced by around 5% - 10% of all CLL patients. The prognosis is generally poor, with a median survival of about 10 months. For further information see Jain P, and O'Brien S. (2012) in their paper, 'Richter's transformation in chronic lymphocytic leukemia'.

the former might allow for people to live tolerable and productive lives in the face of the kind of existential uncertainty that characterizes chronic, often progressive, and sometimes terminal diseases. This work evidenced examples of all three coping strategies:

*The old cliché Life is Short really comes into play with us, I try to live my life the best way that I can. Being a good and kind person as much as possible and really enjoying myself and my family (IOB Survey Respondent 118).*

*I have toddler twins, so I am aggressively taking responsibility for my own future. I realize that I cannot really control it, but I will do whatever is within my control. CLL adds to my uncertainty about the future, but it has not meant planning my life around it. Even during treatment, I kept working and took only a few days off over a period of several months for treatment (including out-of-state travel...) (IOB Survey Respondent 122).*

*I used to have great plans and ambitions, and that is an important part of being human I think. Have though really struggled with fatigue and wellness, still watch and wait. Ability to complete plans is often undermined by state of wellness so eventually plans become a bit pointless. Just getting through is about as far as things go (IOB Survey Respondent 148).*

On balance, however, there was a greater emphasis among patients on expressions of at least trying to live in the present with renewed appreciation of lives no longer taken for granted, although the chronic and unpredictable nature of the disease and the need for recurrent treatment means it is often difficult to maintain this as a consistent philosophy. Many patients adopt the strategy of foreshortening future plans according to treatment cycles/average life expectation statistics for CLL:

*I noticed a dramatic change in my time-sense immediately after diagnosis. My long-term dreams evaporated. I no longer looked at a small house, for instance, and thought, "I'd like to live there when I retire." My forward glance has now*

*shortened to a couple of years, as I will likely need to be treated again by the end of 2014 (IOB Survey Respondent 116).*

## **Perspectives: Metaphor and the Liminal Experience**

Given the cultural predilection for war and battle metaphors surrounding cancer, CLL's status as a systemic blood-borne malignancy working at molecular level and infiltrating the bone locates it in a bleak metaphorical landscape. 'Bad to the bone', 'bad blood', 'in the blood' are all phrases used to connote that something (usually bad or unpleasant) is fixed into the body at the deepest level possible, genetically coded and unchangeable, and in constant and unceasing systemic circulation around the body. There is no solid tumour to "attack" in blood cancers. The abject and widely understood fear of cancer 'spreading' (also fixed as a metaphor for creeping corruption in social life) is irrelevant when the conduit for your cancer flows around every part of your body anyway. Those of us with blood cancer present as wholly cancerous bodies. We do not have tumours that can be isolated from the rest of our bodies and either removed or targeted specifically (although are constantly aware that they may come later in the form of secondary cancers).

Leukaemia is 'in deep' to the marrow, and constantly circulating. In progressive disease, and in remission, blood tests will constantly monitor its status, underpinning an uneasy relationship with our blood that at once recognizes its fundamental life-giving nature yet is characterized by an ongoing cycle of anxiety and speculation. It keeps us alive, but carries the corruption that may ultimately kill us. If being 'bad to the bone' is not enough to amplify liminality, then a

constant state of immune-suppression will suffice. CLL patients live among the immunosuppressed at the best of times, but acute phases of disease such as during and after chemo-immunotherapy can leave patients severely neutropenic and prone to sepsis<sup>61</sup>. To feel constantly at risk of infection is socially alienating and sets one apart (try travelling on a plane wearing a mask). This paranoia-inducing state can leave one feeling metaphorically like a 'borderless country', 'defenceless', vulnerable to 'invasion'. In an increasingly paranoid globalised environment where the metaphor of viral spread and invasion looms large, again the liminality of immunosuppression can be amplified by the language that defines our broader cultural understanding. Sadie Plant locates the metaphor of infection as central to late capitalist language of control:

Paranoia has moved on since the sixties: even the rivers of blood are now HIV positive. Foreign bodies are ever more virulent and dangerous, insidious invasions of unknown variety threaten every political edifice. The allergic reaction to this state of emergency is security integration, migration policy and bio-control: the medico-military complex (Plant and Land, 1994: no page).

Susan Sontag has famously explored the impact of metaphor on living with cancer and AIDS, and found it wanting in its reductive view of illness, and unhelpful in the way it positions the ill. "We are not being invaded. The body is not a battlefield. The ill are neither unavoidable casualties, nor the enemy" (Sontag, 2002: 180). For those of us already living in liminality, such metaphors simply reinforce a defamiliarised territory of 'peace' we can no longer inhabit.

<sup>61</sup> Susceptibility to infection among CLL patients is secondary both to the disease and its treatment. Multiple factors are involved including hypogammaglobulinaemia, neutropenia, impaired T-cell and natural killer cell function and defective complement activity. See Eichhorst et al. (2011) Chronic lymphocytic leukemia: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up, written for the European Society for Medical Oncology and published in the *Annals of Oncology*, 2011, for further information.

## **Perspective: Biographical Disruption and Narrative Reconstruction**

### **Online**

*...When routine blood work revealed a high white count, I knew it must be some type of leukemia. Of course, I panicked and a quote from Tolstoy's "The Death of Ivan Ilyich" popped into my head: "It cannot be, but it is" (IOB Survey Respondent 37).*

There can hardly be a better way of describing the paradoxical moment of the unimaginable made real than the Tolstoy quote invoked at the moment of diagnosis for this respondent.

Diagnosis with a potentially fatal disease locates us in exactly that impossible conceptual bind.

It simply *'cannot be'*, but the business of dealing with the fact that *'it is'* begins immediately, and often requires a radical re-writing of a previously imagined (or at least assumed) future.

Previous perspective sections in this chapter have explored CLL patients' online responses to diagnosis through information seeking practices in the newly diagnosed, the often vexed power relations of knowledge and expertise between informed patients and their doctors, and the experiences of liminality from which these practices are enacted for patients. At the heart of all of these issues lies the process of adjusting from health to illness. The two translations so far have shown how circulating narratives in the network have the potential to transport radically different versions or experiences of CLL across narrative boundaries. This perspective looks at the impact of the transition from health to illness as a form of biographical disruption, and explores the notion of narrative reconstruction as a strategy for managing it that I argue is evolving in the practices of narrative exchange online.

## **'It cannot be': CLL as Biographical Disruption**

*Being a disease with no easy cure, the diagnosis affected my life greatly. I quit my job, tried to keep it a secret, terminated some friendships, drastically changed my eating and drinking habits, and experience many sleepless nights. CLL topics and the great wealth of information from Chaya Venkat helped me cope immensely (IOB Respondent 96).*

Several of the respondent comments looked at so far begin with the sense of extreme shock at a diagnosis with CLL. A sense of life literally fragmenting as conveyed by the above response to the far-reaching impact a CLL diagnosis had on their life. The rupture experienced on diagnosis with a chronic illness can be experienced as “a tear in the fabric of one’s life that can suddenly bring into question all of the assumptions upon which it was based” (Radley, 2004: 145). Such a sudden and catastrophic shift in one’s sense of place in the world forces a reflection on what unexamined assumptions and behaviour might have held it in place prior to diagnosis. Mike Bury (1982) draws on Giddens’s notion of the ‘critical situation’ (1979) to locate chronic illness as radical disturbance of everyday life, a form of what he refers to as “biographical disruption” (Bury, 1982:169). Corbin and Strauss (1987) sort the consequent biographical trauma into three dimensions – biographical time, concept of self and bodily capacities (cited in Radley, 2004:145). These dimensions underpin the uncertainties that plague those newly diagnosed with a chronic illness such as CLL. How long will I live? Who will I be now I have cancer? What will I be able to do – can I still work, play, socialize, care for myself and others..? Familiar with post-diagnostic disruption myself, I asked survey respondents to reflect on the impact of diagnosis on their sense of time. There was widespread expression of the challenges faced by patients trying to plan their lives, both in the short-term in the face of the ongoing inconclusive

nature of CLL:

*My planning is mostly short term as even during remission life is interrupted by medical concerns, infections etc. (IOB respondent 257).*

*As someone who has always looked forward (having the memory retention of a gold fish it's difficult to look back!) this is THE most difficult thing to deal with (IOB respondent 229).*

*I find it hard not knowing what is likely to happen and when. It is difficult not to think at the start of treatment it will be over in 6 months but it doesn't work like that. Am I going to be able to look after myself in a years [sic] 2 years 5 years? I have not looked online or blogs in case they are offputting (IOB respondent 224).*

Many respondents reported struggling with uncertainty about the future on diagnosis, but what seems like a violent disruption to one person may be absorbed as just another life-event to be dealt with to another in a form of biographical continuity rather than disruption as Simon Williams (2000) notes, and the following (relatively rare) response indicates:

*CLL is just another bump in the road for me (IOB respondent 22).*

Variables such as age at diagnosis, staging and prognosis obviously have some potential influence on a response to diagnosis, but reactions may equally be shaped pre-existing attitudes, beliefs, and expectations. The extent to which people experience their diagnosis as 'biographical disruption' then is always contingent and cannot simply be assumed as a knowable phenomenon. The role of *uncertainty* as a feature of illness experience is widely acknowledged as a powerful phenomenon however (Pierret, 1992; Bury, 1982; Radley, 2004).

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CLL, a chronic, incurable disease with all of its heterogeneous forms and possibilities amplifies the uncertainty of illness with a range of additional questions such as: 'will my disease actually progress?'; 'do I have a genetically aggressive or refractory form of CLL?'; 'can I actually be regarded as 'ill' or 'sick' at certain stages of my disease?'; 'will my reduced immunity allow me to succumb to an opportunistic infection?'; 'will my fatigue, commitment to hospital appointments, treatment, and infections make it impossible for me to work and socialize?'; 'will my treatment (if I need it) damage me irreparably or kill me?'; and 'will this disease radically shorten my life span?'

Williams argues that biography itself has become 'a chronically reflexive theme in conditions of late modernity' (Williams, 2000:61) in which we undertake a constant cycle of biographical revisions, regulations, and improvements in relation to our health (amongst other aspects of our lifestyles). In other words, as late-modern subjects we are re-writing the biography of our bodies in relation to *ourselves* on an ongoing basis. In the reflexive project of the self, suggested by Giddens (1991), illness may feature as one of *many* biographical adjustments in the ongoing construction of embodied selves already tied in to broader notions of risk, regulation, control, taste and status, supporting a view of the web as a kind of "self-help agora" for cancer patients (Orgad, 2000). The current popularity of pathographies that frame a cancer diagnosis as a catalyst for 'improved' attitudes, and behaviours perhaps underscores a fashion for reflexively narrativizing *ourselves* in relation to lifestyle choices.

Underlying narratives of risk often drive obsessions with health and healthy lifestyles.

Increasingly, public insight into the cultures and key themes of medicine and health care



provision is heightened through contact with popular cultural narratives from news, through self-help books, to medical drama and documentary, all edited to produce a constant and dramatic narrative flow of risk and regulation, “typically expressed in formulations of concerted care for the body and its healthfulness, whether for individuals or collectives, as a state of permanent emergency”<sup>62</sup> (Blum, 2011:460). In this sense, informational culture in relation to health issues spreads far beyond a focused project of ‘looking things up’ when we suspect, or are diagnosed with an illness. The constant background noise of health-related narratives in everyday life that perhaps contribute to increasing porosity of the boundaries between medical and lay knowledge, also feeds into a pervasive paranoia about health perhaps most acutely realized when actually diagnosed with a serious illness.

The way an individual responds to illness might be read as an attempt to assert his or her identity in relation to an existing sense of agency: “...autonomy can be observed in how agents manage to maintain a precarious identity with the ability to act so as to ensure the persistence of their agency” (Moreno and Casado, cited in DaRocha and Etxeberria, 2013:67). For example, for a patient already accustomed to independent information seeking in other areas of their lives, managing diagnosis with illness and informing clinical decision-making through self-directed research sustains an existing identity as one who maintains control through strategic assimilation and application of knowledge. Arguably, if maintaining a comfortable identity

<sup>62</sup> Drawing parallels with the logical nexus that housed notions of nuclear deterrence and the cold war in the geopolitical system, Blum notes the particular burdens this places on the system, and the practitioners and clients that operate within it opening up a range of ethical questions around “concerns for governance regarding the quality of care, advice, expertise, information and conflicts between dependency and self-determination” (Blum, 2011:460).

involves retaining faith in the clinician as holder of *all* knowledge in the patient/doctor relationship however, or in a belief that exposure to the narratives of others is a potentially distressing experience best avoided as some respondents have expressed, the agency gained by maintaining a recognizable identity may well turn out to be a risky form of autonomy.

This perspective has demonstrated then that CLL patients live with at the very least a double-articulation of risk, the broader pervading conceptual sense of bodies and health at risk (Giddens, 1991; Beck, 1992; Blum, 2011), and the corporeality of bodies as risky environments through which they must now experience the world. Furthermore, this is an outside world to which, for the most part they will appear as they always have, yet an inner world that is fundamentally changed for them in numerous ways, most of which cannot be planned for or accurately predicted. How they are able to respond to this potentially paralysing vortex of risk and uncertainty will depend to a great extent on their existing attitudes and expectations because however strongly they feel their diagnosis cannot be ... it very definitely is.

### **'...but it is': narrative reconstruction in the networks?**

Reflecting on his diagnosis with prostate cancer, writer Anatole Broyard remembers that "My initial experience of illness was as a series of disconnected shocks, and my first instinct was to try to bring it under control by turning it into a narrative" (Broyard, 1993:308). Broyard's experience was of an acute and aggressive form of prostate cancer, the series of 'disconnected shocks' that defined its relatively short course radically shifting and truncating his particular life

narrative (he died in 1990 following diagnosis in 1989). For most people diagnosed with a chronic disease, the task of re-imagining a life narrative involves revision of plot, structure, and maybe character over time, as opposed to a radically accelerated conclusion. Williams (1984) describes this process as “narrative reconstruction” (Williams, 1984, cited in Radley, 2004:146). People narrativize their illness experience in all sorts of ways from personal imaginings, through everyday conversations to written biographical accounts. Key among the literature surrounding study of the latter is the work of sociologist, cancer patient and heart attack survivor, Arthur Frank who sees narrative as a means of empowering bodies and voices ‘wounded’ and silenced by serious illness and its treatment. For Frank, ‘wounded storytellers’ are members of what he refers to as the ‘remission society’ accommodating amongst others<sup>63</sup>, the chronically ill, the disabled, and anyone who has had cancer (Frank, 1995:8), and producing three dominant types of illness narrative:

Restitution stories attempt to outdistance mortality by rendering illness transitory. Chaos stories are sucked into the undertow of illness and the disasters that attend it. Quest stories meet suffering head on; they accept illness and seek to *use* it. Illness is the occasion of a journey that becomes a quest (Frank, 1995:115).

The value judgement inherent in this triadic typology seems clear. In the *quest*, Frank places emphasis on the active *use* of narrative to heal the wounds inflicted by illness on the self and others. Narrative is located as a resource for facing ‘head on’ the reconstruction of a coherent self, fragmented by traumatic experience. The idea of narrative as constitutive of self has its

<sup>63</sup> These ‘others’ include those living in recover from cardiac events, or from addiction or abuse, and anyone with a disease that requires continual self-monitoring or the management of prosthesis (Frank, 1995:8)

critics though. Crispin Sartwell (2000) cautions us “to resist the impulse to mistake narrative for life” (Woods, 2013:126) whereas Galen Strawson (2004) rejects outright the validity of any assumption that “human beings always conceive of life as a narrative” (Strawson, 2004:428). Paul Atkinson (2009) highlights ambiguity of voice and the role of performance in any narrative act, and is worried about dualistic personal/authentic lifeworld *versus* impersonal institutional discourses encouraged by framing illness narratives as an act of resistance to the silencing potential of the biomedical model (Atkinson, 2009: 2.6). The potential of culturally available or acceptable narrative discourses to marginalize alternatives needs to be considered in relation to narrative categorization of illness experience. CLL patients, diagnosed with a chronic, unpredictable, invisible, incurable disease that can loop from chaos back to order many times in its life cycle often find themselves in this exclusion zone:

*Unlike other types of cancer this one is difficult to accept as a "fight" making one feel helpless to battle it unlike "hard" cancers which have a clearly defined pathway ie diagnosis/treatment/recovery/all clear (IOB Survey Respondent 261).*

Narrative concerns, including post-modern scepticism surrounding the unproblematic alignment of a coherent ‘self’ with narrative technique seemingly have little impact on the enduring popularity of reading and writing pathography however. Some critics even question whether a contemporary philosophical de-centring of the self and meaning creates a vacuum in which “writers and readers find in personal narratives the authenticity and authority that postmodernism denies” (Hunsaker-Hawkins, 188). This may particularly resonate with the sick for whom even a reflexively constructed identity has received quite literally a *body* blow. Anne

Jurecic notes a scholarly emphasis on the importance of the body itself in health narratives “The theories of narrative set forth in the work of Charon, Frank, and Hawkins respect the irreducibility of the writer’s body” (Jurecic, 2012:15). Contemporary biography is, as already acknowledged, constructed in complex socio-cultural environments. Pathography emerges when the continuation of that biography is threatened by the compromises and mortal failings of the body itself, invoking a Cartesian dualism as Hunsaker-Hawkins notes “Illness intensifies the sense of the self: faced with disintegration and death, the self assumes a Cartesian certitude – “I am sick therefore I am” (Hunsaker-Hawkins, 1999:189).

Evangelistic claims for the healing powers of narrative reconstruction, and sceptical critiques notwithstanding, it would appear that many people do benefit at some level from writing and reading about the experiences of serious illness. Psychologist James E. Pennebaker has conducted empirical research on the therapeutic benefits of emotional expression through trauma writing and, whilst seeing its limitations, suggest that the ‘practice of composing’ itself provides a means for organizing an understanding of one’s life and self, and for gaining insight into uncertainty and the unknown (Jurecic, 2012:11). Anne Hunsaker Hawkins has identified three basic types of illness narrative, or pathography: testimonial pathographies, inspired primarily by didactic or altruistic motives; angry pathographies that describe patients' unhappiness with the way they or their illnesses have been treated; and narratives that deal "with finding alternative treatment modalities -modalities that sometimes supplement traditional therapies and sometimes replace them altogether" (McLellan, 1997:101).

So how, if at all, might the concept of narrative reconstruction be read in relation to the circulating narratives in the CLL networks explored in this work? First I will look at that question in the light of the specific features of the disease, before going on to explore more fully a potential need to revisit illness narrative theory in the light of online health communications.

As with a diagnosis with any chronic disease, CLL patients need to re-imagine a life that has become inextricably linked with their illness. Restitution as proffered in Frank's triad of narrative types is not (yet anyway) an option. As Arthur Kleinman notes:

“Chronic illness is more than the sum of the many particular events that occur in an illness career...The trajectory of chronic illness assimilates to a life course, contributing so intimately to the development of a particular life that illness becomes inseparable from life history” (Kleinman, 1989:278).

Where an unpredictable chronic illness like CLL – an incurable cancer with heterogeneous patterns of progression and outcomes<sup>64</sup> - becomes part of that life history, it presents obvious challenges in re-narrativizing *any* form of coherent, linear, teleological structure surrounding future life plans. This was a commonly reported phenomenon among survey respondents:

*I have adjusted to living mainly in the present. I plan only in the short term and have accepted that things are often cancelled. It's very disappointing but I try and take pleasure from the small things that I do manage (IOB Survey Respondent 256).*

<sup>64</sup> Interesting work is emerging questioning whether more successful approaches to treating many cancers, and a recognition that the impacts and effects of the disease and its treatments extend way beyond the treatment period, might mean that cancer in general should be regarded as a chronic disease. See Witter and LeBas (2008) for their overview of cancer as a chronic disease in M. D. Anderson Cancer Center's publication, *Oncolog: Report to Physicians* published in April, 2008.

It may be the case that the only truly empowering form of re-narrativizing for a CLL patient may be that of re-imagining the self as one who can learn to accept and accommodate a life made vulnerable, uncertain, and problematic in ways that are often difficult for others to comprehend. In some ways this could be read as the kind of re-narrativizing that might fit Frank's notion of a quest. Whether or not all patients are conscious of an ontological or ethical need to elevate that beyond the personal level of managing life with a difficult disease as implied in Frank's notion of the quest is contestable, although the very act of circulating and sharing personal narratives online and putting them into contact with multiple alternative narratives indicates a desire for public-facing and collaborative forms of narrativizing personal illness. As this work has noted, online narrativizing in the information economy can be read as a reflexive act, based more on transient, multi-faceted and ephemeral exchanges than the more sustained existential writings alluded to by Frank. Comments by respondents in the previous CLL Online Chapter also indicate that not all narrative sharing is expressed as an ethically motivated practice. I want to argue in the next section however that the more dialogic form of illness narratives shared in online communities make any potential benefits of shared experience readily available as a by-product or network effect whether or not their posting was primarily motivated by an ethical drive.

## **Digital Narrative Reconstruction: A New Paradigm?**

Diagnosed with a brain tumour in September 2012, digital artist and lecturer Salvatore Iaconesi accessed his digital medical records in search of a cure. Obligated to “crack” the files from their closed form to an open format for sharing, Iaconesi used them to spark a remarkable process beginning with the setting up of his site ‘Mia Cura: A Multi-Media Network for Cure’ (see screenshot in Figure 15) prefaced with the following aim:

Just today I have been able to share the data about my health condition (about my brain cancer) with 3 doctors. 2 of them already replied. I have been able to do it because the data used open, accessible formats: they have been able to open the files using their computers, their tablets...I will progressively publish all the replies I will receive, using open formats, so that anyone with my same disease will be able to benefit from the solutions I will find (Iaconesi, 2010).



Image removed due to copyright restrictions

**Figure 15: IACONESI , S. (2013). 'La Mia Cura' open source cure [Screenshot] 22/04/2013. [Online] Available at: <http://opensourcecureforcancer.com/> [Accessed: 17/03/2013].**

Successful 'Me centred' network sites such as laconesi's, user-generated personal accounts of illness on YouTube, and blogs with facilities to comment produce networks quite different to the more diffuse communality imagined in 'virtual communities' (Rheingold, 1993). As with laconesi, one individual is central to the network, but their own narrative accommodates the comments and responses of others. laconesi's site publishes his x-rays, explains his situation, and invites responses under highly variable interpretations of 'cure'. Responses are grouped into over 300 suggested 'cures' ranging from acidity to zebrafish and posted by brain surgeons, through artists, to people with similar experiences and those who are just interested in contributing. I suggest that this ongoing re-shaping of individual narratives in response to the multiple narratives they intersect with applies just as readily to the more short-form exchanges

taking place in online support community dialogues.

On the face of it, Frank's argument that ill people attempt to re-locate themselves learn by "hearing themselves tell their stories, absorbing others' reactions, and experiencing their stories being shared" (Frank, 1997:133) is not far removed from what we see happening in online pathographies, whether in blog form, a collaborative project such as laconesi's, or the shorter form exchanges more often seen in support communities and listservs. Frank and other proponents of the therapeutic value of illness narratives focus on their healing potential, not just of the illness itself but also of the perceived disempowering impacts of institutionalized approaches to care. As Atkinson warns us though, this view of treatment as having as much power to silence as the disease itself, and of narrative as providing the power to regain a voice can validate a reductive subject/object division between health care and the patient experience. Furthermore, such views need to be read in the light of changing power relations between doctors and their patients in a digital era as explored in chapter 2 of this work. Although this evolution is a slow one, and CLL patients in this research reported varying experiences in their own clinical relationships, attitudes and expectations towards the roles played by doctors and patients in relation to disease knowledge and management have changed considerably since Frank published *the Wounded Storyteller* in 1997.

I don't want to appear to throw the baby out with the bathwater here though. Despite obvious movements in a direction away from oppressive medical regimes, this work has shown consistently that many CLL patients *do* in fact feel silenced and voiceless in response to a

perceived lack of understanding of the issues faced on diagnosis. We are not yet in a position to claim that such silencing doesn't or won't still occur at some level. The question is more one of whether singular narrative quests are necessarily the only or indeed the most effective tool to help regain those voices now that more open-ended and rhizomatic narrative potentials are available through the digital health narrative? This chapter has already demonstrated how circulation of narratives such as Brian Koffman's 'Good Cancer' blog post, and a research paper 'Invisible, Incurable and Inconclusive' (Evans et al., 2011) put patients' own health narratives into dialogue with narratives that address the difficulties they face yet are written by and articulate the way CLL is enacted by representatives from the very institutions perceived as holding the power to silence them in the first place. Gaining understanding of the different objects of CLL in this way, learning to contextualize their own narratives in relation to the broader ones that shape their treatment and care alongside absorbing the narratives of other patients surely has the potential to frame the digital illness narrative as something more than just an empowering response to an act of oppression visited by disease *and* its treatments? I will return to this in conclusion, after exploring some more narrative translations en route with this question in mind.

As many respondents in this chapter have shown however, the CLL networks online have to some extent helped them to negotiate the difficulties faced in this respect on diagnosis (and beyond) by sharing narratives with fellow patients and (in some cases) professionals. Exposure to a flow of circulating personal and professional narratives can reduce a sense of isolation, exemplify alternative models for coping, and open up multiple versions of CLL against which to

consider one's own personal story. Network actors approach this in different ways, and I want to focus in the final translation of this chapter on a longitudinal case study of a network actor's use of narrative to transition from newly diagnosed information seeker to key agent of support for the newly diagnosed.

### **Translation: A Newly Diagnosed Actor in the Network**

Very regularly in the CLL support networks, a plea for help, support and advice will appear from a newly diagnosed patient or a loved one of someone recently diagnosed. The requests take as many different forms as those posting them, but they are shot through with universal themes of shock, confusion, disbelief, disorientation and anxiety. Without fail, these pleas for help are responded to - very often by key actors in the community who have responded to similar pleas many times before.

The closing translation selected for this chapter takes the form of a small case study of a particular actor in the CLL networks, mapping excerpts from three of his postings over a three year period to demonstrate a basic timeline of online narrative adjustment to a CLL diagnosis. Diagnosed in 2011, Hairbear is now a major actor in the UK and global CLL networks, heading up online support groups, organizing face to face meetings with patients and clinicians, and operating as an active CLL advocate. The excerpts that follow are headed up under the original titles of the postings and trace his journey from a recently diagnosed CLL 'newbie' reaching out for advice through a narrative approach, through a process of acceptance raising interesting

questions about what forms an adjustment to a liminal life might take, to a much later response to another newly diagnosed patient seeking help in 2013. All of the postings were made to the Macmillan CLL/SLL support group:

## **Making the Adjustment**

On 27 Jan 2011, new community member Hairbear made the following update entitled 'Making the Adjustment', to his blog 'CLL NEWBIE' on the Macmillan CLL/SLL community forum:

*Hello all thanks for welcoming me into the community. I didn't realise that there could be so many of us in one place! With my limited knowledge I've found it easy to find my way around, well done techies. I was shocked how quickly I have been able to meet other patients of my age with CLL; we appear to be quite thin on the ground. Just exchanging information about symptoms we share that the haemos seem to dismiss within our age group, has taken away some of the fear that doubt creates. Sharing in the broader experiences of the community has already cleared much of the fog that still lingers following my diagnosis. I now know I do have a place where I can share the ups and downs caused by our disease (Hairbear, January, 2011).*

Hairbear's opening paragraph acknowledges the relief expressed by many patients at finding a support group where they can communicate with others sharing a CLL diagnosis. Immediately, attention is drawn to the role played by technical support in the networks in providing a navigable interface. So often black-boxed in discussions in online support, Hairbear makes it clear how dependent community users are on those working behind the scenes to facilitate

such communication.

The relative paucity of similar younger CLL patients can be a problem for those diagnosed in their forties and fifties (or younger in very rare cases), and the sense amongst this group that we are sometimes ‘lumped in’ with the generally older demographic receiving a CLL diagnosis in terms of clinical approach and available information is expressed here in Hairbear’s comment about the “dismissal” by haematologists of certain symptoms “within our age group”. As acknowledged earlier, CLL is generally speaking an older person’s disease. There is no doubting that this remains a devastating diagnosis at any age, but the difference between being diagnosed in one’s forties and at the average age of 72 is considerable in terms of potential impact on lifestyle, lifespan expectations, and disease management. The sense of liminality is heightened by living with the unquantified potential of a significantly truncated lifespan and by the impact on working/earning potential that a diagnosis with CLL in middle-age can bring. Doubt about the future can, as Hairbear notes, invoke fear, but for him the ability to share in “the broader experiences of the community” to some extent ameliorates that fear, dispersing some of the post-diagnostic “fog” and allowing him to reflect on the early process of coming to terms with the disease:

*It’s taken a while but I think I’ve managed to come to terms with the disease, what was holding me back was partly my own denial, combined with the complex nature of what diagnosis really means. Having to learn a new language just to interpret what CLL is, has taken the longest. At first you can’t see the wood for the trees. There’s so much conflicting information out there and it’s written in different medical languages, so each time you visit, you come away more confused and afraid (Hairbear, January, 2011).*

Hairbear's description here of the complex nature of a CLL diagnosis and the disorienting and often frightening process of researching the disease online accords with many of the comments made by the survey respondents in this and the previous chapter. As noted, not all patients wish to pursue an active independent approach to researching their disease for a number of reasons from existing beliefs in the hierarchies of medical knowledge exchange, through mistrust of online information to self-preservation in the face of unwelcome information. Hairbear never questions his need to interpret "what CLL is" for himself, but is clear about the challenges of learning to navigate both the language of medical discourse and the vagaries of conflicting information. There is a sense in the reflection that things get better as confidence with the language grows, as does the ability to discern which information we might rely on. The wood emerges from the trees slowly in this narrative. Arguably with most CLL experiences this can only ever truly be interpreted as the wood of uncertainty becoming visible through the trees of desire for exact answers, but coming to that conclusion may be a longer game than the perspective of Hairbear's 'newbie' narrative allows for. What Hairbear does acknowledge with an articulacy that will resonate strongly with fellow community members is the difficulty experienced by the newly diagnosed in coming to terms with "watch and wait":

*Perhaps learning to cope with "watch and wait" is one of the hardest! Everything you think you understand about cancer is turned on its head by this approach. To have to let the disease develop within you, whilst it gets stronger and you get weaker, must be one of the greatest adjustments to perceived convention that we make. Thankfully we ought to get respite for a good while after the time treatment comes. But it's a bit of a double edged sword really; if you want treatment you can't have it yet, and when you don't you have little choice. At least we have time to be involved in the decision as to what therapy will best suit us (Hairbear, January, 2011).*

In this chapter, I have already explored the acknowledgement of these difficulties faced by CLL patients in the circulating narrative of Evans and colleagues (2011) 'Invisible, Inconclusive and Incurable' research paper. Early after my own diagnosis I told a colleague that my leukaemia was not being treated immediately. With a look of abject horror, she informed me emphatically that my doctor was either negligent or stupid (or both), and that I should seek a second opinion as a matter of urgency if I wished to stay alive. Such is the received wisdom that cancer must be treated aggressively and immediately that no amount of explanation on my part would convince her that I wasn't being duped into an early demise by a medical charlatan. When diagnosed with CLL, the paradox of having to accommodate it while it progresses produces a cognitive dissonance that is even harder to come terms with. As Hairbear powerfully puts it "*To have to let the disease develop within you, whilst it gets stronger and you get weaker, must be one of the greatest adjustments to perceived convention that we make*" (Hairbear, January, 2011).

Certainly that uneasy sense of sleeping with the enemy is a key theme in the diagnostic period and beyond amongst CLL patients, and Hairbear's efforts to rationalise that through the potential of a decent remission ultimately involute into his narrative acknowledgement of lack of control over treatment timing. The knowledge that CLL treatment, however good the remission period may be, is ultimately a *palliative* rather than a curative response at present underscores this reflection, and again feeds back into the sense of liminality and uncertainty suffered by CLL patients and acknowledged previously in this chapter. Any narrative reconstruction taking place, as it is here by Hairbear in the early days of his diagnosis, must



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accommodate that profound uncertainty as part of a post-diagnostic life moving forward. Seeing that form of narrative modelled in support communities has the potential to assist others with their own approaches as the following survey respondent indicates:

*... I was terrified, for the first year I had no support till I found a US site of like sufferers who were at the same stage as me, a god send we were on the same page! (IOB Survey Respondent 207)*

Hairbear closes his reflective posting by summing up his response to finding the community in the wake of his diagnosis. Fellow members are addressed as “friends” in a clear appeal to community values, and a forthright plea for narratives outlining the strategies employed by fellow members to adjust to “the new shape” of their lives acknowledges biographical disruption and a perceived need for narrative reconstruction of those lives:

*Cancer has opened my eyes to the effects on the patient, their loved ones, friends and lives. Nobody wants to be a member of this club, but having had no choice, I am glad to have found this address. I look forward for the opportunity of sharing highs and lows with many new friends within the wider community. Please let me know what has helped you adjust to the new shape of your lives. Take care, an optimistic newbie (Hairbear, January, 2011).*

Whether the optimism expressed by this self-confessed “newbie” refers to the expectations of support, the impact of the disease on his life, or both is left unclear, but that the posting ends on a note of clearly articulated optimism is important. This reflective narrative has expressed fear, anxiety, denial, confusion, and some loss of agency, but it is presented as the rational and determined reflection of someone who is not willing to be crushed or silenced in the face of a

diagnosis and who will overcome what challenges he confronts. In reaching out to others for their stories of adjustment, there is an assumption that others too will have taken or will be taking this way forward in learning to live with CLL. At the same time as reaching out to be enabled by others, Hairbear's narrative is in its own way potentially *en-abling* through modelling a narrative strategy for coping. The underlying story here is one of learning to cope, to manage conflict and challenge, and to collaborate through the sharing of stories. In setting up this model, Hairbear is working to make the support networks more active and dynamic. The next posting shows how the narrative of diagnosis progresses through a reflection on 'normalizing' CLL as a part of everyday life.

### **'Is this Normal?'**

Some seven months on in August, 2011, Hairbear makes another entry to his CLL Newbie blog on the Macmillan site reflecting on the phenomenon of 'normalizing' his disease experience:

*Looking at how I think about having CLL these days I seem to be thinking differently? I appear no longer concerned about the procedure of giving a little blood for routine testing, I even never seem to give a second thought about what the disease may be doing. Whether my counts may have altered dramatically from the last time. I know it's slowly marching (creeping up), but don't seem to be phased. The day to day symptoms that were new are now just a part of me, having adjusted my routine I seem to have forgotten what things were like before, so now feel normal again. Is this normal, or am I in a form of denial again? (Hairbear, August 2011)*

The tendency to 'normalize' or come to accept a diagnosis and accommodate it has been addressed earlier in this work, and Hairbear's narrative reflections on this phenomenon, followed by his questioning of the definition of 'normality' when living in diagnosis "is this normal, or am I in a form of denial again?" alludes strongly to the liminality of a CLL diagnosis. Hairbear questions whether the benchmarks for what is perceived as 'normal' in the life of someone living with CLL actually do change, or whether perceiving the symptoms and impacts of the disease on daily life as a new 'normal' is somehow a form of *denial* of the real impact of a diagnosis with a chronic, incurable leukaemia on our lives. He attempts to answer his own question within a framework of altered expectations and new routines which, practiced daily, congeal over time into a new 'normal':

*I guess we adjust and become the "new normal". The altered expectations of the future, the being unwell, the new routine, the precautions, the medical environment and the necessary new knowledge are all assimilated. Incorporated and connected and become nothing more than part of your normal day (Hairbear, August, 2011).*

Locating this sense of normalizing that would once have felt entirely abnormal in a more specific symptom of living with CLL, Hairbear focuses on the phenomenon of infection experienced by CLL patients who are significantly immune-compromised:

*I seem to notice changes but they don't stand out, it's understood and expected. So as infection has become more frequent and harder to shake, I realise that has crept up on me too. Am I imagining how normal it feels? Because I'm sure something, that before would have seemed major, now is just another day and barely noticed, is this normal, or does this happen to us all? I remember when diagnosed, finding out about infection precaution and again thinking " how the hell am I going to discipline myself to take this on board"? Well I did and it must help with some, but not all. Now I am familiar with*

*many more antibiotics than before. I think this is why my interest has been peaked [sic] by much of the new research into combating pathogens, the search for a universal flu vaccine and even immunotherapy for CLL (Hairbear, August, 2011).*

CLL patients are constantly prone to infection, and what's more – to infections that a competent immune system could fight off with ease, but that could be potentially fatal in the immune-suppressed. This brings with it a sense of real vulnerability and constant risk in the face of everyday pathogens. The need to 'manage' exposure to infection risk is productive of a constant sense of the body as a 'borderless' country, and one that needs to be protected constantly against the threat of invasion. This can have a negative effect on one's sense of resilience and spontaneity in the world, and can be isolating. All CLL patients know this, and Hairbear appeals to that knowledge amongst community members through his narrative reflection, before rolling it into an exploration of recent research into fighting infection generally, and more specifically to CLL:

*There is work happening with T-cells, immunotherapy, and CLL...*

*<http://www.cllglobal.org/bios/cooper.htm>*

*Dr. Gribben at Barts--*

*[http://www.cllglobal.org/research/alliance/updates/hosing\\_shpall\\_gribben.htm](http://www.cllglobal.org/research/alliance/updates/hosing_shpall_gribben.htm)*

*Kipps, Castros et al have been working on a number of CLL vaccines like ISF35 etc...*

*[http://www.memqenbio.com/technology/files/Memqen\\_ASCO\\_2011\\_Poster.pdf](http://www.memqenbio.com/technology/files/Memqen_ASCO_2011_Poster.pdf)*

*(Hairbear, August, 2011).*

The provision of links so that readers can visit the pages for themselves, and the contextualizing of the CLL specific work within a broader portfolio of work and links on

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infection generally encourages readers to think about the world of pathogens and immunity in the broader sense. Yes, CLL reduces our immunity, but what do we understand about immunity, infection, and the current issues relating to them in the first place? Hairbear links to research coming out of Cardiff into phyto-chemicals and Manuka honey, and to work on drug resistant pathogens. “Salmonella strain, known as S. Kentucky, has developed resistance to the antibiotic Ciprofloxacin, often used for treating severe Salmonella cases.” Discerning between a BBC and an NHS article linked to in his narrative:

*<http://www.bbc.co.uk/news/health-14386654>*

*UK- NHS on the subject -<http://www.nhs.uk/news/2011/08August/Pages/kentucky-drug-resistant-salmonella-epidemiology.aspx>*

*The NHS on the subject proved a much better read (Hairbear, August, 2011).*

Hairbear summarizes findings that the drug resistant pathogens originate in North Africa and the Middle-East, probably as a result of over-use of antibiotics in poultry farming, and appear to be trafficked by travel, poultry and some fruit and vegetables, contextualizing the risk for CLL patients:

*As we CLLers already employ preventative hygiene procedures around food and especially raw fruit and vegetables, that the NHS suggest. I would suspect that we are best prepared to avoid such a minuscule chance. However the trend does show a small increase (Hairbear, August, 2011).*

Infection in CLL, and the precautions required to minimize the negative impact of that on our lives is located as just one part of a broader machine of immunity/infection/treatment. The story of Hairbear's coming to terms with those impacts on his life is narrated as part of a complex, interconnected world of science, biology, agriculture, transport, hygiene and pharmacology. Hairbear questions his shifting perception of 'normality' within this bigger-world picture, using research and knowledge assimilation as a means to understanding how he needs to re-shape his own world in relation to the broader worlds that shape it post diagnosis: "There seems to be much going on in the field of research that may produce results that improve our quality of life". As well as hope, there is realism though. The research, the knowledge, understanding the bigger picture might help to comprehend and manage the contingencies on a particular disease, but it doesn't remove the anxiety and fear of living with a progressive, incurable cancer altogether, and Hairbear is careful to acknowledge this in closing his narrative reflection on adjustment:

*None of it's gone away, the discomforts are all still here. As is the hammer over my head with knowledge that treatment will come. Maybe I'm just having a good day or maybe we do just adjust. Take care (Hairbear, August, 2011).*

The reader of this narrative learns that adjustment is possible, that it may vary in degrees from day to day and is not necessarily a linear process, that (for Hairbear) it has been aided by seeking a more complex understanding of the multiple impacts of the disease, but that the basic challenge of living with this uncertain disease remains central however well we may adjust. This is a positive model for other readers, but by no means unattainable or unrealistic in

its avoidance of potentially alienating claims of self-realization or 'closure' that might exclude those still struggling with diagnosis. This sense of hanging on to the difficult parts of diagnosis whilst attempting to move forward into a fulfilling post-diagnostic life is evident in the final posting in this Translation case study.

## **RE: New Diagnosis**

In November, 2013, almost four years on from his own diagnosis, Hairbear posted a response to a call for help and advice from a Macmillan community member following a recent diagnosis. The appeal for help is raw and immediate, and differs in that sense from the more reflective postings of Hairbear's 'newbie' blog entries analysed here. For ethical reasons, I will not replicate the original posting here, but am concerned more with Hairbear's response, the trajectory exemplified through his three postings from newly diagnosed and seeking help and advice to a key actor in the CLL networks dispensing advice to other newly diagnosed patients. In welcoming the new patient to the group, Hairbear acknowledges from experience the sense of fear that so often accompanies a CLL diagnosis, and introduces his own CLL 'credentials':

*Welcome to our group it is very scary and I can recall myself how debilitating that feeling is. I was diagnosed four years following a CT scan investigating other matters and have not required treatment yet (Hairbear, 2013c).*

This is followed by a brief explanation of CLL diagnostics in relation to the basic biochemistry of the disease that precedes personal recognition of the anxieties of awaiting a diagnostic blood

result:

*How unfortunate to have your results on Christmas Eve, I will be thinking of you. Waiting is very much a part of having CLL you may experience much waiting for even when everything is confirmed CLL is only treated when it has to be, so many here will be able to share how they cope with waiting. Right now you can probably not feel anything other than fear and how this news is making you feel (Hairbear, 2013c).*

Hairbear invokes a sense of community and personal concern in this response whilst acknowledging the likelihood of feeling overwhelmed by fear at this very early stage of diagnosis. The recipient is reassured that 'right now' this is an appropriate response, but – by example- that it will eventually subside. As we have seen with Hairbear's previous narratives, one of his coping strategies has been that of learning about the disease. Knowing something about how the disease works and what to expect in terms of progression and management is presented as a positive step that the newly diagnosed can take to help themselves:

*learning a little about CLL can be very helpful and explain what to expect. As CLL tends to progress very slowly you should have a lot of time to take it all in, nothing will suddenly go bump in the night. Here are some very current and understandable sources of UK patient information that may help you in the beginning. I am sure others will join you soon to share a little.*

*Leukaemia & Lymphoma Research: website is a good place for early learning, it is supported with very recently updated information in booklets, Audio and videos and an extensive website written in an understandable manner. <http://leukaemialymphomaresearch.org.uk/information/leukaemia/chronic-lymphocytic-leukaemia> (Hairbear, 2013c).*

The sense that self-acquired knowledge and understanding can increase agency and contribute to a less traumatic period of adjustment to diagnosis is implicit here. Also implicitly



acknowledged is the challenge and potential dangers of increasing fear inherent in unguided searching at an early stage of diagnosis, as reflected on in Hairbear's first blog posting explored earlier in this case study. Hairbear goes on to provide the following list of links, filtered and selected as appropriate for a newly diagnosed patient venturing out to research CLL online, and already sorted into a range of aspects of the disease covering a range of dimensions from the physiological to the emotional:

*Chronic Lymphocytic Leukaemia (CLL)*

*[http://leukaemialymphomaresearch.org.uk/sites/default/files/cll\\_july\\_2012\\_3.pdf](http://leukaemialymphomaresearch.org.uk/sites/default/files/cll_july_2012_3.pdf)*

*Information for those newly diagnosed with a blood cancer*

*<http://leukaemialymphomaresearch.org.uk/newly-diagnosed-blood-cancer>*

*Watch and Wait: Monitoring While Treatment Is Not Necessary*

*[http://leukaemialymphomaresearch.org.uk/sites/default/files/watch\\_and\\_wait\\_dec\\_2011\\_0.pdf](http://leukaemialymphomaresearch.org.uk/sites/default/files/watch_and_wait_dec_2011_0.pdf)*

*This is brief and current introduction to and overview of CLL written by Professor Pettitt for the UK Lymphoma Association also a good place to start. <http://goo.gl/fQ0ul>*

*Healthtalkonline, uses video snippets from CLL patients and medics to support information*

*Reactions to the diagnosis*

*<http://www.healthtalkonline.org/Cancer/Leukaemia/Topic/3765/>*

*Other people's reactions to the diagnosis*

*<http://www.healthtalkonline.org/Cancer/Leukaemia/Topic/3767/>*

*Watch and wait <http://www.healthtalkonline.org/Cancer/Leukaemia/Topic/3792/>*

*Please just throw anything that's on your mind to the group, there are many here who can give you feedback. You are not alone here (Hairbear, 2013c).*

With the final comment, the assimilation of research information in relation to the recipients own situation is presented as something that works effectively when it is dialogic and put into action in the broader collaborative narrative setting of the group. Drawing perhaps on the memory of his own early experiences of groping in 'the fog' that descends after diagnosis, of not being able to see 'the wood for the trees', and the difficulties of assimilating a new language and conflicting information, Hairbear attempts here to provide the kind of guidance that might ameliorate some of the terror that often accompanies solo online research in the early stages of diagnosis.

From scared patient, reflecting on a new diagnosis and reaching out to others for their stories, to accomplished guide and advocate for the newly diagnosed, this case study has outlined the narrative evolution of a key actor in the networks. Hairbear's use of reflective narrative, rhetorical questioning, collaborative mode of address, and enmeshing his ongoing story of diagnosis and reflexive adjustment into the broader networks it connects to hypertextually exemplify a form of evolving digital illness narrative. It is no surprise that Hairbear has become a key actor in the networks, and a significant mediator, linking people and the disease across network boundaries, and creating and holding together new nodes in the network. What motivates and equips some people to adopt this role and not others is beyond the scope of this research, but is flagged up for future exploration as it is central to an understanding of how successful network effects in cancer support might be replicated where they remain wanting.

## Chapter Summary

This chapter has explored various enactments of a CLL diagnosis through circulating narratives in the network. In translation, Brian Koffman's 'Good Cancer' blog post, Evans et al.'s 'Invisible, Incurable and Inconclusive' research paper, and the case study of a patient's own postings to a CLL support community alongside patient voices from the survey and networks have demonstrated something of the range, intersection and effects of circulating narratives of diagnosis in the CLL networks.

Fieldwork has clearly shown that patient experiences of a CLL diagnosis are too often poor. Patients often feel that their sense of shock and devastation on diagnosis doesn't correlate with some doctors' uninformative and unsupportive manner in conveying the diagnosis. The widespread inconsistencies in clinical knowledge and approaches to treatment of CLL reported across the networks, in tandem with a perceived downplaying of the severity of CLL by clinicians very likely contributes to this group's strong sense of dissatisfaction and low reported emotional well-being in the relatively rare quality of life studies that exist for CLL patients (Shanafelt, 2007). Furthermore, many patients report being placed in an impossible conceptual bind by being told that CLL is 'a good cancer' which, for a significant amount of them simply doesn't turn out to be the case. A common response to this lack of support and information on diagnosis is to go online and access support networks. Findings in this chapter show that among those online patients studied, internet use seemed to be of very real benefit in coming to terms with a CLL diagnosis in most cases. In Perspectives, I look at the impact of an increasing lay

medical literacy on patient/clinician relations in relation to hierarchies of knowledge exchange.

Levels of clinical knowledge about CLL outside of the specialist setting are patchy at best, with many patients reporting the poorest levels of knowledge among GPs and family doctors. Even among some general haematologists, levels of knowledge and treatment approaches were reported as inconsistent, and it is not uncommon for CLL patients online to become as knowledgeable about the disease and its politics, if not more so, than their doctors.

Technocultural shifts in the patient/clinician relationship are filtering through slowly into daily practice, and with varying degrees of acceptance from clinicians it would seem. Although some patients reported feeling overwhelmed, confused or excluded by online information and support narratives, they were in a significant minority. Their views are extremely important however, as they may well be representative of a much wider group of offline voices not captured by this work.

In emphasizing narrative responses to tensions between clinical and patient enactments of a CLL diagnosis in the blog post and research paper selected for Translations, this section has shown some of the strategies adopted in online support networks to bring multiple and often conflicting enactments of CLL together for consideration. Accompanying perspectives have explored work on different dimensions of disease definition using a triadic model of subjective illness, biomedical disease and socio-legal sickness. It seems that the heterogenous and unpredictable nature of CLL locates it as a disease that defies easy categorization at the best of times, perhaps exacerbating existing tensions between subjective and biomedical enactments. Both Brian Koffman's blog and Evans and colleague's paper mediate between these

enactments, considering patient dissatisfaction with levels of clinical information and support against time constraints and professional attitudes to disease severity contingent on institutional and professional haematological practice in the clinical setting.

Evans and colleagues' observations of CLL as a disease whose invisibility, incurability, and inconclusiveness places patients in a liminal space between cultural understandings of illness and health shows the *specific* difficulties this patient group faces in coming to terms with diagnosis. This seems particularly acute for CLL patients in the watch and wait phase of their disease, and these challenges have been read alongside perspectives in this chapter exploring the processes of accommodating diagnosis in relation to theories of biographical disruption and narrative reconstruction. The final Translation shows how an individual CLL patient has used narrative strategies in an online support community to negotiate a transition from a terrified newly diagnosed member to a key network actor, sharing information and links to multiple narrative enactments of CLL online, and assisting both himself and the newly diagnosed to adjust to life with the disease.

In demonstrating how patients and professionals have mobilized the internet to construct and share narratives of coming to terms with diagnosis in varying contexts, this chapter has worked towards advancing the argument that new forms of illness narratives in an informational age in which multiple narrative enactments intersect can act to create broader multidisciplinary understandings of the varied aspects of disease experience.

Given the complex biographical impact of a CLL diagnosis however, alongside unequal access to online facilities in the disease's older demographic, simply relying on the fact that patients will, as my own GP suggested I did, 'go away and look it up on the internet' is by no means a satisfactory overall answer to this group's often unmet need for diagnostic information and support. As already noted, this research is self-selecting of patients already online. It is impossible to calculate how many CLL patients do not use the internet, but it is undoubtedly a far greater number that are represented here as acknowledged by the following survey respondent:

*Before internet info, I was given a brochure by my consultant. I think we are very cut off in Cornwall for information. What about CLL people without the internet? (IOB Survey Respondent 2)*

This is an area that CLL patient advocate groups online could perhaps influence in collaboration with regional consultants through communication with primary health care providers, and it is an issue that urgently demands further research if future generations of CLL patients are to fare better than their current counterparts in terms of informational access and emotional well-being. The above respondent also draws attention to the issue of inequities in treatment approaches and access to specialist clinical expertise and trials according to geographical location, another common theme emerging in the online survey and support networks, and one that will be explored in the following chapters.

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For the time being, it would appear that most CLL patients already online are using circulating narratives to their benefit in understanding the various enactments that define their disease, and accessing the information and support that underpins pro-active approaches to their experiences of a diagnosis with CLL.

## Chapter 4: Prognosis

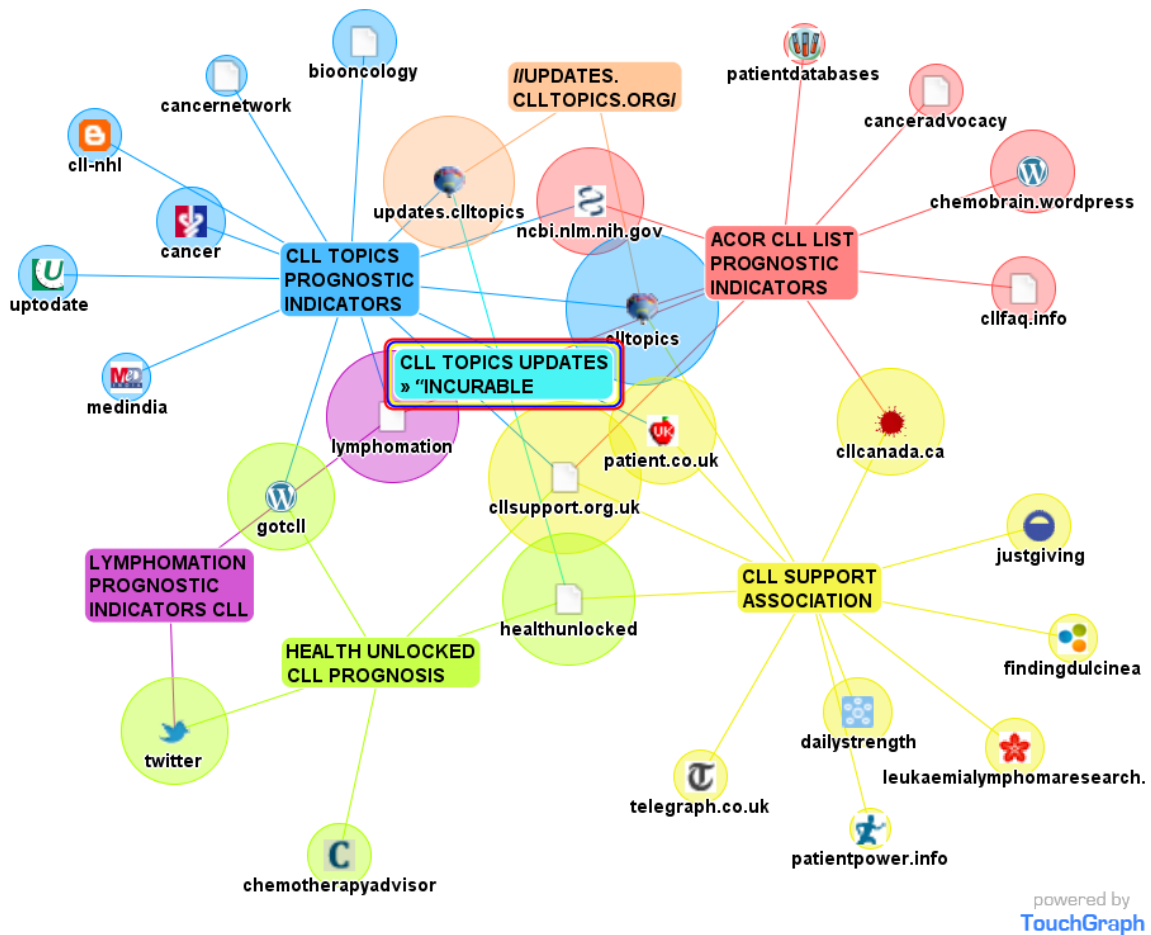


Figure 16: TOUCHGRAPH (2015) network connections between nodes addressed in ‘Prognosis’ chapter [Network Map]. [Online] Available at: [www.touchgraph.com](http://www.touchgraph.com) [Accessed 04/03/2015].



## **Introduction: Living in Prognosis: The Bigger Picture**

*...prognostic markers for me cause a lot of research to look for survivability times that seem to be different for all, hard to realize how much time is left...(IOB Survey Respondent 51).*

Employing a range of voices from the survey, online forums, and my own experiences, alongside key sites identified by users and network mapping tools, this chapter will show how people are forming and utilizing networks to help them to negotiate complex translations across the worlds of cells, science, time, pharmacology, medicine and the day to day business of living with a life-threatening disease in relation to prognosis and prediction of their likely disease course.

Prognostic testing in CLL is becoming more sophisticated as biomedical understanding of the disease advances rapidly, and the range of tests available for typing, grading, and predicting likely progress of their disease is expanding. The boundaries between issues of being diagnosed and receiving a prognosis are barely discernible to the patient, so enmeshed are they, and my separating them out into two discrete areas may seem to some to be an artificial distinction. However, CLL prognosis can be a kinetic affair, evolving in some cases as the disease progresses, as treatments effect clonal evolution, and as residual disease begins to return following treatments. The impacts of prognostic testing and knowledge extend way beyond the moment of diagnosis in reality, and way beyond the clinical sphere too.

Of equal importance is the potential psychological impact of advanced prognostic knowledge on CLL patients. Does knowledge of likely disease course and outcome necessarily benefit a patient in the early stages of disease if it doesn't offer a greater degree of control over how that progress might play out? How much benefit might it afford if it can't predict future developments in treatment that might alter predicted courses anyway? These questions require careful consideration of the psychology of day-to-day disease management for those living with chronic diseases. As with diagnosis, they draw acutely on issues of perceptions of time in the lifeworlds of the chronically ill. As long as a gap remains between prognostication, and ability to significantly influence or halt disease progression, CLL patients will have to negotiate the yawning chasm between knowledge and control. As already demonstrated, contemporary life with CLL is very much a life in the interstices – between illness and health, between old treatments and new, between expert care and access to novel protocols and traditional generalist provision. As also demonstrated, and as will become clearer throughout this work, times are rapidly changing in cancer care *per se*, and in CLL care specifically. Any allusion to the impact of rapidly advancing genetic knowledge in disease treatment must address the issue of patients living in a transitional present where patients are exposed to varied experiences between traditional and evolving approaches to prognostication.

As the previous chapter has shown, life with CLL becomes a liminal theatre upon whose stage we perform the functions of everyday life, whilst fully aware of the spectre of grave illness loitering in the wings. As one survey respondent put it, *"I have grown to see it as the monkey that is on my shoulder, always waiting to drop in"* (IOB Survey respondent 66). Prognostic and

predictive indicators offer the closest alternative we have to stage directions for the timing and management of its entrance, but this remains something of an improvised script.

Metaphorical monkeys and theatrical spectres hint at the crisis of meaning that 'living in prognosis' (Lochlann-Jain, 2007) invokes. However much technical knowledge patients might accrue, and whatever their degree of collaborative decision making in relation to treatment, questions still remain about how to think about shaping a life without any teleological certainty (always putative anyway of course), and how to interpret the deferred meaning of prognostication when the signification of one's *actual* death slides constantly beneath the signifiers of generic descriptors and statistics. Despite, or maybe because of, the dissonance between statistical and actual experiences of life and death in prognosis, it is an obvious preoccupation for many people living with a life-threatening disease. As a 'chronic' cancer, CLL as a rule gives those living with it more time to consider the implications of their prognosis on both treatment and life choices. Unsurprisingly then, the CLL networks buzz with topics surrounding prognosis and prognostic indicators from a range of perspectives reflected in the rich responses yielded in the survey element of data collection. In total 160 respondents provided some 8,600 words describing their use of online resources surrounding prognosis.

The survey responses were invaluable in sketching out the broader map of sites and themes for this area of the study. The following respondents allude to some of the major sites utilized, and demonstrate the impact of information gained from them in understanding and coming to

terms with their own prognostic indicators:

*Discussion of prognosis comes up frequently at all sites and at all meetings. ...Best resource? CLL topics again. (IOB Survey Respondent 168)*

*A few months after diagnosis, our son found the list of CLL Specialist on the ACOR site through searching the Internet. I went to Mayo Clinic for the testing of Fish, Zap 70, etc. My CLL Specialist suggested joining ACOR's CLL List. My learning began at that point. The four months prior to that I was in panic mode believing I was going to die shortly...(IOB Survey Respondent 124).*

*The dear, departed Dr. Terry Hamblin contributed to 2 of the 3 lists that I subscribed to. When I learned, 2 years after diagnosis, that I was unmutated, I had a brief bout of hysteria until some correspondence with Dr. Hamblin calmed me down. In retrospect, I know that his "prognosis" was based on extremely limited data, and should perhaps have not been taken so seriously, but the variability of everyone's experience (as I have learned via the lists) and the fact that there as so many new and exciting clinical trials underway (which I have also learned via the lists) have allowed me to live my life in a more measured and un-hysterical fashion (IOB Survey Respondent 26).*

*.... CLL TOPICS was probably the most helpful in developing my understanding of the various prognostic markers. Having now read many research articles and followed journeys of a many CLL patients who write their stories in the forums and their blogs, I have come to appreciate the limitations of the prognostic markers...(IOB Survey Respondent 86).*

Respondents identified other sites (such as CLL Canada) in the survey, but the most active nodes selected for mapping in this area included the ACOR list, CLL Topics, the late Terry Hamblin's blog 'Mutations of Mortality', and CLLSA Health Unlocked.

This chapter will address the issues above as they manifest in the circulating narratives of CLL online. Perspectives will address current prognostication in CLL, the important shift from prognosis in terms of life expectancy to prediction of a disease's likely course in order to underpin strategic treatment planning, issues surrounding knowledge and power in prognosis, and what it means to live in risky bodies. Translations will look at a number of narratives circulating online from the most frequently mentioned sites in the survey, addressing prognosis in CLL from scientific advice and advocacy, through specialist advice to patients' own narratives as they accommodate the inscriptions of science and medicine.

## **Perspectives: Prognosis in CLL**

As already stated, the field of CLL prognostication and treatment is rapidly evolving, and a brief overview of the current state of genetic research underpinning advanced prognostication in CLL specifically will help to set the scene for the perspectives and translations explored in this chapter.

Whole genome sequencing provides raw data on all six billion nucleotides in an individual's DNA. The process has been applied specifically to CLL cells under the direction of Dr. Stephan Stilgenbauer (University of Ulm, Germany). The CLL cells are separated out from patient blood samples, and the chromosomes unraveled so that the nucleotide sequence of each gene can be determined. All human cells are exposed to a number of external and toxic stressors that

trigger mutations and change genetic coding at cellular level. These mutations are often silent, or repaired before they do any critical damage. However, some of them make significant genetic alterations leading to the growth of cancer cells. Comparative readings of mutated cells and healthy “normal” cells in the same patient allow researchers to identify deletions and abnormalities in the tumour DNA. Repeating the process across a range of patients allows for comparison of disease progression and treatment responses in relation to those genetic mutations related to CLL.

It is openly acknowledged in current research that the prognostic techniques currently employed can be something of a blunt instrument in relation to the dynamic genetic complexities of CLL that genome sequencing has made visible:

Current diagnostic approaches to treatment selection, response monitoring, and relapse prediction are limited to single genes and apply only to a minority of hematologic cancers. This is at odds with modern concepts of tumor propagation and maintenance, which propose that every cell in an individual cancer is characterized by a combination of mutation events that comprise tumorigenic (driver) mutations, passive (passenger) mutations, and possibly predisposing germline risk variants (Schuh, A. et al., 2012: 4191).

Schuh et al. used whole genome sequencing to track clonal evolution in three CLL patients subject to recurrent therapies, concluding that: “genomewide sequencing will become an effective approach to monitor disease progression systematically and also prospectively” (Schuh et al, 2012: 4195). The authors hypothesize that this will be far-reaching, directing future trials, clinical decisions, fundamentally altering treatment protocols, and contributing to

more cost-effective care of CLL patients with improved outcomes. But what does this mean for patients currently living with CLL?

Prognostic testing at diagnosis varies globally according to local protocol. In any case, either at diagnosis or at the point at which treatment is deemed imminent, patients will currently undergo cytogenetic/fluorescence in situ hybridization (FISH) analysis. This genetic test reveals a range of markers providing baseline predictions of likely disease progression and response to treatment. In the US, this is part of a standard diagnostic work-up. In the UK, most patients wanting this amount of prognostic detail prior to needing treatment would currently have to pay a specialist research centre for a test unless fortunate enough to have one as their local hospital. This seemingly unequal right to access cytogenetic information at the point of diagnosis results in a good deal of debate in CLL networks online. However, despite the relative sophistication of current flow cytometry, and significant advances in the treatment of CLL, relapse remains the major cause of mortality and specialists recognize an urgent need to improve response prediction to new and traditional therapies so that effective treatment choices can be made in line with Anna Schuh's optimistic predictions. Inevitably, CLL patients are caught up in the time lag between the advance of scientific knowledge and the health care systems that deliver the results and in reality a range of prognostic practices can be seen playing out in the support network narratives. One conceptual change underpinning practice is filtering through into network debate however, and that is the distinction between prognosis as impact on life expectancy, and prediction as a benchmark for therapeutic decision-making.

## **Perspectives: Motivations for Knowing: Prognosis or Prediction?**

Up until 1999, when prognostic tests began to be applied in trials, evaluating prognostic factors was largely a retrospective process. As Terry Hamblin puts it: 'They were tested on samples that were sometimes more than 20 years old from patients who were treated in many different ways, often suboptimally' (Hamblin, 2007). On the cusp of an era of personalized medicine however, biomarkers function as much more than prognostic indicators of likely potential lifespan. Predictive biomarkers can help physicians and their patients negotiate strategies for care based on individual disease profiles, irrespective of their broader prognostic signs:

Whereas prognostic biomarkers indicate the overall clinical course of the disease irrespective of treatment, predictive biomarkers pinpoint patients most likely to respond to a specific therapy... ideally predicting treatment response before it is given, thereby protecting the patient from adverse effects caused by ineffective drugs (Alsolami et al., 2013: 362).

As Schuh and colleagues' (2012) work shows, an upturn in the availability of predictive biomarkers is likely as genomic knowledge advances. Currently, clinical use of CLL predictive markers is limited to the monitoring of minimal residual disease (MRD) following treatment as a surrogate marker for overall survival in trials (or to identify patients who might benefit from maintenance therapy), and the use of deletions and/or mutations of TP53 located at chromosome 17p13.1 to predict a poor response to chemotherapy amongst this group (*ibid*).



If intervention in clinical decision making at this level may intuitively appear outside the remit of patients in general, this work reveals plenty of network evidence to show patients actively seeking out new treatment regimes, clinical trials and even switching care providers based on the implications of predictive and prognostic markers and the way their clinicians approach them:

*I have changed oncologists again in part because I was not entirely satisfied with the minimal prognostic testing and lack of communication about the results (IOB Survey Respondent 122).*

It is clear that in many cases these decisions, and the knowledge required to understand and make them, are significantly influenced by online research and discussion. However, not all respondents were positive about the benefits of researching prognostics online, with some advising caution:

*If I believed my prognosis I would have died last year. Ignore them and develop a positive attitude to beating cancer in your own way, the web gets in the way of this (IOB Survey respondent 156).*

This respondent actually couches the web as a *barrier* to developing autonomous coping strategies for, in this case, a poor prognosis already outlived. This shows that the imagined community of CLL online, with its untrammelled narrative flows of experience and information, is just as capable of exerting a negative influence on some users as it is a positive one on others. Prognosis is concerned with very personal parameters of life and death, yet is only ever

representable as something 'other' to an audience - someone else's statistics, someone else's story. It is easy to see why, outside of a model for predictive treatment planning, many patients find exposing themselves to wider spheres of prognostic abstraction difficult, or even harmful to negotiate.

In the early days of my own diagnosis, I was desperate to know what the future might hold for me as a CLL patient, and embarked on my own (often stormy) voyage of prognostic discovery online. I want to start this chapter with two Translations each exploring one of two particular narratives I encountered in the search for prognostic information. The first, 'Making sense of prognostic factors in CLL', by Consultant Haematologist Professor Andrew Pettit (2008) is an introductory outline aimed at the newly diagnosed CLL patient available on the CLLSA UK site<sup>65</sup>. The second, 'How I Treat CLL Patients up Front' is a paper by CLL specialist Professor John Gribben, published in clinical haematological journal 'Blood' in (2010), and linked to the 'Prognosis' section of lymphoma advocacy site<sup>66</sup>. Whilst both are written by CLL specialists, the former is specifically aimed at patients, whilst the latter is published in a professional peer-reviewed journal, and focuses sharply on the issues of prognosis and prediction from the clinician's perspective.

<sup>65</sup> <http://www.cllsupport.org.uk/03%20Prognostic%20factors.pdf>

<sup>66</sup> <http://bit.ly/favAVV>

## Translations: 'How long have I got?' (Making Sense of Prognostic Factors in CLL)

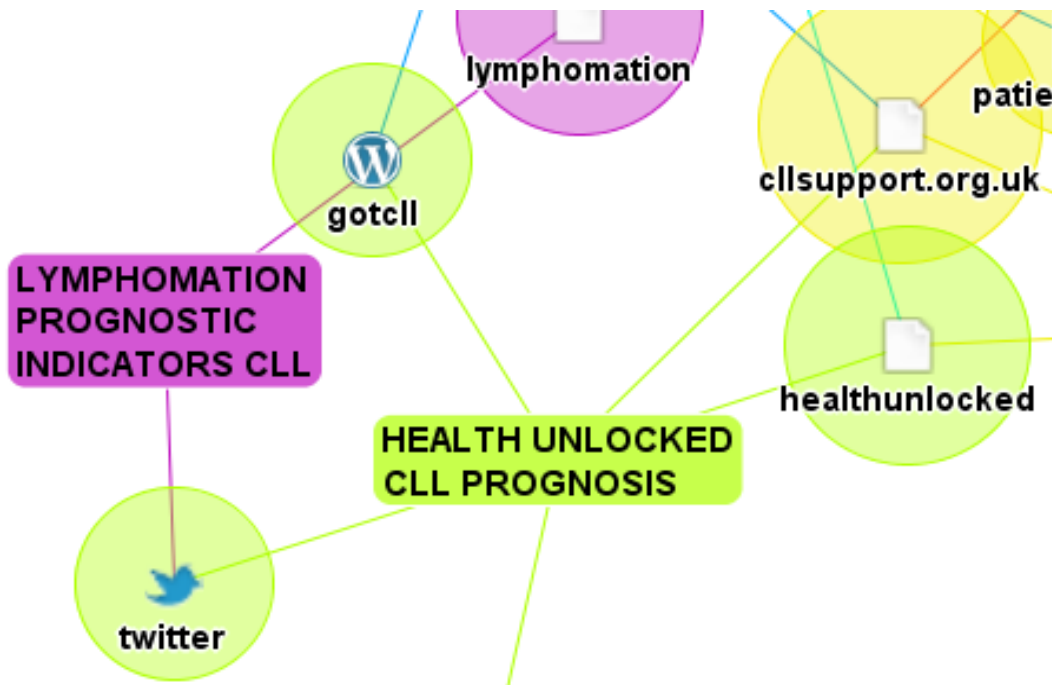


Figure 17: TOUCHGRAP (2015) network connections from CLL Support site (CLLSA UK) to Lymphomation site [Network Map]. [Online] Available at: [www.touchgraph.com](http://www.touchgraph.com) [Accessed 04/03/2015].

In the days immediately following diagnosis, having been sent home by my GP with very little information about CLL other than its incurable status and instructions to 'look it up on the internet', my main preoccupation was my prognosis, or 'how long will I live?' I spent much of the time awaiting my first consultation obsessively familiarizing myself with staging and median survival times, trying desperately to relate them to my increasingly unrecognizable life. I must have visited hundreds of sites in those early days, from personal blogs to institutional

information pages, all of them presenting information in different formats, from different perspectives, and for different audiences. Traumatized by the diagnosis of an incurable, life-threatening disease for which I had no frame of reference, I was at the mercy of the generic, the dated, and the sometimes erroneous information online. Information and median survival times based on earlier trials of continually evolving treatment protocols make for distressing reading for the recently diagnosed, and the difficulties inherent in making sense of them is articulated by the following respondent:

*I am a librarian and have become concerned about the older info which is online. Because all treatments are evolving quickly I wonder how the average person will sift through it all (IOB Respondent 64).*

The question of how the newly diagnosed negotiate this terrain is of profound importance to the understanding of initiation into the network cultures of any disease, and is an issue directly concerning key network actors. In CLL networks online, various advocacy and support sites take different approaches to presenting information for patient-readers. There is strong evidence of efforts to provide distinct information for the newly diagnosed or 'newbies', for whom a much higher degree of informational gatekeeping may be assumed to be beneficial. Of course, questions must be asked about who guards the informational gates for the newly diagnosed, and why. Putting issues of control and power aside for now, it is generally assumed to be a well-motivated desire aimed at reducing the potential distress inherent in going it alone when still reeling from diagnosis, and not necessarily conversant with the skills of internet research in general (the median age of diagnosis with CLL is 72).

The only lead I had been given by my GP was the CLLSA UK site, and it is to this site that I turn in the first instance to briefly outline its presentation of the staging systems and key prognostic indicators in CLL. The first information on prognostic indicators I read was 'Making sense of prognostic factors in CLL', a dedicated introductory outline for patients written for the site by Consultant Haematologist Professor Andrew Pettitt.

Although written in June, 2008, many of the tests addressed in the document still remain core to the current portfolio of major prognostic and predictive testing and concerns, although Zap-70<sup>67</sup> has fallen out of favour somewhat and CD38 expression is controversial, the reasons for which will be addressed later in the chapter. The document introduces patients to a range of prognostic issues such as variability between patients; clinical staging; lymphocyte doubling time; chromosomal abnormalities; IgVH mutation and CD38; Zap 70; importance of 17p (p53) deletion in predicting response to therapy; and discordance (the co-presence of conflicting 'good' and 'bad' markers). In the 'Summary and Practical Advice', Professor Pettit suggests that:

For newly diagnosed patients requiring a broad picture of how their disease is likely to behave, a panel of prognostic tests is probably required including FISH for 17p-, 11q-, +12 and 13q-, and ideally at least two of the following: IgVH status, CD38 or ZAP-70. These tests are not routinely funded by the NHS and are usually only available at centres that specialise in CLL. However, most hospitals should have links with such a centre (Pettit, 2008:4).

<sup>67</sup> These more recent findings are summarized by a clinical research paper charting the progress of prognostics for CLL in the face of evolving genomic knowledge entitled 'Clinical application of targeted and genome-wide technologies: can we predict treatment responses in chronic lymphocytic leukemia?' (Alsolami et. Al, 2013) and linked to CLL forum CLLSA Health Unlocked by members in early 2014, demonstrating how recent research is located and circulated by active individual mediators/translators in the networks thus keeping them continually updated.

Julia Kennedy

For myself and others treated outside of specialist centres however, this wish list of prognostic tests turns out to be far from what is actually available at our local hospitals. In my case, FISH testing for chromosomal abnormalities was reserved for patients about to enter treatment, IgVH testing for mutational status - an accurate predictor of disease progression, was not budgeted for outside of clinical trials, as was the case with Zap-70 testing (Zap-70 is a tyrosine kinase and crucial molecule for the selective activation of T cells in downstream pathways, the test for which was considered useful in indicating likely disease progress). Initially somewhat confused and concerned by the inconsistencies, online discussion with other UK patients soon led me to understand that this was a common experience for those treated outside the major research centres. Discussions about seeking second opinions from a CLL Specialist, generally located in the big research centres are common across the communities (not just in the UK, but globally), and raise pertinent questions about inconsistencies in cancer care addressed throughout this work.

Armed then with baseline blood tests, and the results from a basic flow cytometry test to identify a range of markers associated with the disease, I was confirmed as definitively having CLL, and put on 'watch and wait' to be monitored at three monthly appointments with my consultant. I was told I would not get any further prognostic testing until my CLL needed treating.

## **Translation: 'How I Treat CLL Up Front' (Clinical Enactments of Prognosis)**

As Figure 17 (p228 above) shows, when mapped using the TouchGraph tool, CLLSAUK, ACOR, and CLL Topics were linked to the Lymphomation.org site pages on prognostic indicators in CLL.

Lymphomation.org was set up in 2002 by Karl Schwartz and the Patients Against Lymphoma group with the express aim of patient advocacy. It provides information on all lymphomas including CLL. The CLL section operates as a database linking out to current resources such as research papers, and sites providing information and support. The section on prognosis clearly shifts the emphasis from abstract prognostication to treatment specific prediction:

Oncology does not need more prognostic factors, it needs predictive factors that are treatment-regimen specific. Prognostic factors are unlikely to be used unless they are therapeutically relevant ... (Lymphomation.org).

Drawing on the work of CLL specialist and active network presence Rick Furman, emphasis is placed on the limitations of prognostic markers as useful only in identifying which curve a patient might be on and not where on a median survival curve they might be located. “[For CLL] nothing is more helpful than the pace of your disease” (*ibid*).

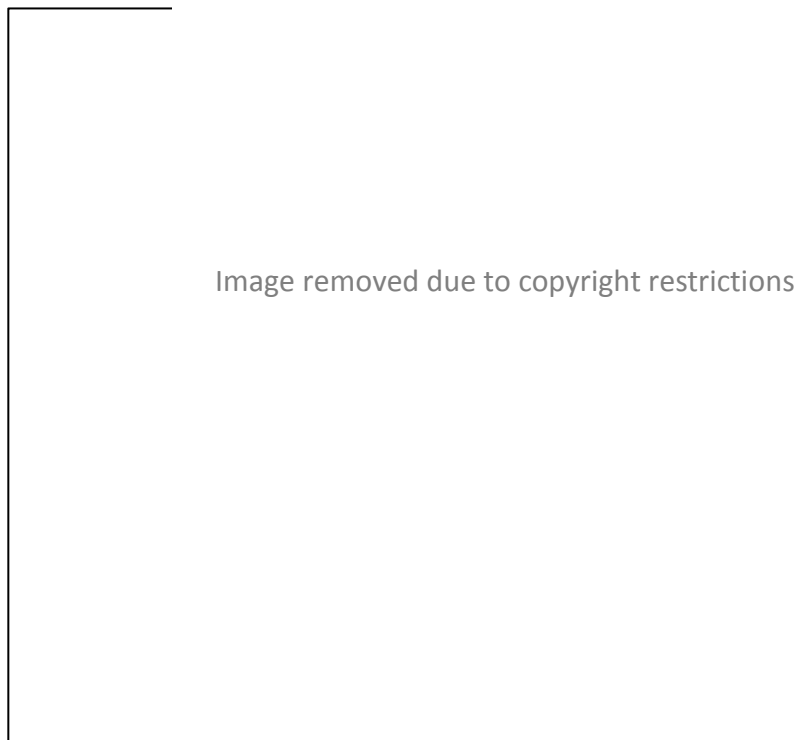
This is followed by a link to a paper published in the clinical haematological journal 'Blood' in (2010) by CLL specialist John Gribben: 'How I treat CLL up front' (2010) focuses sharply on issues of prognosis and prediction from the clinician's perspective. Although Gribben points out the paradox of high patient demand for prognostic testing despite its notorious ineffectiveness in accurately predicting precise outcomes for individuals, he acknowledges that he would want access to "as much prognostic information as possible for planning purposes" (Gribben, 2010:31) were he to be diagnosed with CLL himself. However, in this paper, Gribben is careful to point out the difficulties in accessing IgVH testing, the inconsistencies inherent in current approaches to Zap70 testing, and disagreement surrounding the prognostic implications of CD38 results which change over time. Notable also are his observations surrounding patient motivation for prognosis, and the need to counsel for the potential impact of disappointing results. This is coded in terms of the clinical time and expertise needed to explain to patients the significance of prognostic testing:

My own experience is that patients usually request these tests, hoping that they will have good prognostic markers; the finding of poor-risk features can often lead to increased anxiety, while not changing management, and this requires considerable time in clinic explaining the potential significance of the findings. It is, therefore, important that those caring for CLL patients have a full understanding of the clinical significance of any investigation that has been ordered (Gribben, 2010: 32).

As with many of the research papers circulating in the CLL networks online, this paper is written primarily for a clinical audience. Linked to a patient advocacy site, it becomes a resource for patients too. CLL patient readers able to follow the paper in its entirety will encounter a narrative perspective on CLL that differs from their own, a different 'object' of their disease



(Law and Singleton, 2004). Understanding prognostic testing as a clinician sees it can be helpful for patients negotiating testing with their own doctors. The following table (see Figure 18, below), taken from the same paper and site outlines some of the more complex variables that might produce a poor prognosis in patients:



**Figure 18: GRIBBEN, J. (2010) Poor prognostic factors in CLL, from 'How I Treat CLL Upfront'. Blood Journal [Online] 115(2), 187–197. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2941409/> and linked to CLL page on Lymphomation site.**

The table is just one stage of translation in the multiple iterations of information circulating around prognosis in CLL. Signs are first summarily translated from the body to clinical staging or laboratory tests and reiterated as median survival/likely response to treatment ('good' or 'poor'), then contextualized (in this case) in a clinical paper on disease management for

physicians, before re-iteration in the networks as a patient resource. It is on the basis of these translations that the personal narratives of living with CLL in the network draw for their own iterations, ‘what does this mean for me in the context of my life?’, ‘what might it mean for you and yours?’

Sites like Lymphomation.org might be taken for granted by those seeking information on lymphoma online, but setting up and maintaining an informational hub of this nature involves a vast amount of work by dedicated actors. The site is an incredibly rich, rhizomatic or ‘mycorrhizal’<sup>68</sup> resource, although one that may require some advanced knowledge or patience in navigation in comparison to sites that produce information already filtered for the newly diagnosed.

Curating recent thinking on all the known lymphoma types, and linking out to a range of relevant resources, it is edited in the sense that links have already been selected as appropriate by someone acting in the role of mediator. Information is sorted into thematic categories covering the major aspects of disease definition, approaches to treatment, and ongoing research with multiple hyperlinks. These hyperlinks function as more than informational cul-de-sacs of course, leading instead ever deeper into dense networks of information. As a new patient, I was somewhat overwhelmed at first by the sheer scale of the information reservoir

<sup>68</sup> Yrjö Engeström suggests that mycorrhizal structures offer a better metaphor than rhizomatic structures, where mycorrhizae are symbiotic fungal roots living with plant roots that can spread underground for miles – see Engeström’s paper, ‘From Teams to Knots: Activity-theoretical studies of collaboration and learning at work’ (2008) for further discussion of this theoretical approach.

pooling into this site, although I personally found it preferable to sites that actively attempted to direct my research practices as a new patient. As the survey work shows however, many patients find solo exploratory searching without a guide unhelpful, whilst others are autonomous in their search practices, using multiple sites located through Google searches and hyperlinks. Unfiltered access to prognostic information online can come at a cost however, as the following perspective outlines.

### **Perspectives: Fore-knowing...Power or Cruelty?**

Lest my retrospective narrativizing of the key sites encountered in my early research surrounding prognostics online has rendered it into a neat and linear process, let me be clear – it was not. I bounced like a pinball from site to site in those early days, was convinced my death was imminent, was confounded often by conflicting information, was floored by encounters with personal narratives of people dying from CLL (a final blog entry from a CLL patient in his early sixties about to leave his home for the last time to die in a hospice from multi-organ failure following infection quite literally had me sobbing on the kitchen floor), and encouraged by stories of people who were surviving way beyond their allocated median survival times. The knowledge I have gained since has helped me to avoid the pinball effect of uninformed internet research, and to cast off the misplaced sense of *imminent* mortality, but that is not to say that I don't still sometimes find myself in extremely challenging places.

Julia Kennedy

Many newly diagnosed patients, or those facing key milestones in the course of their disease will inevitably encounter 'median survival times' as they try to locate themselves somewhere on a prognostic curve. Anyone who has ever attempted to relate their own life to a median survival time will understand the impact this can have, particularly in the early stages of diagnosis where the nature and discourse of generic prognosis can be both alien and terrifying to comprehend.

"How long do you think I will live?" I asked my Consultant plainly during my first meeting with him.

I drew (too quickly) on the knowledge gained from mean survival statistics on the internet to prompt him out of his measured consideration with my own suggestion.

"Ten years..? Maybe less..?"

He told me that he didn't know, pausing before adding that he thought it "...a brave question."

I didn't think so. I think it would have been much braver *not* to ask. Like most people facing unexpected news of a life potentially foreshortened, I was not able to reach immediately (nor yet in fact) into bold reserves of calm acceptance, of *que sera sera*. I wanted to *know* everything about my disease from its specific genetic encoding to its probable timeline - a timeline now bound into a double helix with the timeline of my life. It strikes me now as odd that I never hungered for this degree of anticipatory control over the future prior to diagnosis, but nothing transforms one's own mortality from mere abstraction to cold, hard reality quite as effectively

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as being diagnosed with a progressive, incurable disease. *Prognosis*, fore-knowing, fore-seeing the likely course of my disease, is what I *think* I want, although I italicize the possibility that this is dangerous desire, and that maybe I should be careful what I wish for.

Academic Susan Sontag experienced 3 episodes of cancer over three decades. Having survived advanced stage metastatic breast cancer in the seventies, and ovarian cancer in the nineties, in early 2004 she was diagnosed with MDS, an acute and deadly form of leukaemia<sup>69</sup>. Nine months later she was dead. Anne Jurecic describes Sontag's belief that she could control her cancers over the years through knowledge and force of will as a form of 'magical thinking'. After witnessing his mother's distress when the unambiguity of the dismal prognosis for her MDS finally ruptured any potential for 'magical thinking', her son David Reiff asks the question in the context of life-threatening illness, "Is information, or knowing, power or is it cruelty?" (Reiff, 2008: 53).

The implications of this question hover around the responses of CLL patients to questions of prognosis. The inevitable statistical abyss confronting individuals with *any* disease notwithstanding, CLL presents as a particularly slippery customer with many variations in disease presentation and potential outcome. Even in an evolving landscape of more personalized disease markers, no aggregate will speak truth to the power of death and dying as

<sup>69</sup> MDS (myelodysplastic syndrome) often results from genetic mutations in the bone marrow caused by prior chemotherapy regimes. See Zhou, Y. et al. (2012) for a broader view on Therapy-related myeloid neoplasms following fludarabine, cyclophosphamide, and rituximab (FCR) treatment in patients with chronic lymphocytic leukemia/small lymphocytic lymphoma, in *Modern Pathology*, 2012.

ultimately individual experiences. Indeed, the heterogeneity and mutability of CLL contribute to a sense of its current unknowability, leading some patients to make a conscious decision not to engage with prognostication until it becomes a necessity to guide treatment:

*I have never asked for my "markers" other than the counts that are checked routinely. I don't feel it is necessary to know until I need treatment and by the time I do, my disease may have evolved. If I do test, and it's bad news, I would worry more. If it's good news, I would feel horribly cheated if it turns out bad... I will not undergo treatment without as much information as possible, but I don't need it now. I have read that attitude from others on the ACOR list, so I feel it is a good decision (IOB Survey Respondent 68).*

Outlining the perceived perils of engaging emotionally with mutable prognostic information, this respondent confirms that their thinking has been influenced by and tested against the experiential narratives of others in a trusted online forum such as ACOR, a major node in the CLL network.

## **Perspectives: Tagging the Diseased Self**

The practice of contributors signing themselves off using their prognostic indicators and treatment histories as they might list their qualifications after their names in forums such as ACOR is testament to the wide range of disease experiences represented by community members. Importantly, it allows members new and old to negotiate myriad patient narratives according their authors' particular disease characteristics and histories. I currently sign off in

Julia Kennedy

relevant forums with my age, cytogenetic status, and treatment regime to date, as 'Julia Kennedy, age 54, diagnosed March 2011, 13q-, 6 rounds FCR November 2013 to May, 2014'. I have no idea how this tagline will evolve over the coming years. On the ACOR forum, some long term members are signing off with several lines of data, documenting over 15 years of changing disease status and treatments. These taglines themselves, into which shorthand form are condensed so many complex personal narratives of disease, provide a fascinating archive of evolving biomedical knowledge and changing treatment protocols in their own right and support Faith McLellan's observation that online health narratives are 'an amalgamation of journal and lab report' (McLellan, 1997: 101).

The practice of defining the diseased self online through listing biomarkers and disease experience as 'qualifications' in this way raises interesting questions about the impact of unfolding genetic knowledge in shaping human narratives of ancestry, identity and health. As we have seen, the genetic mutations occurring in the genesis and progression of cancer determine prognosis and, increasingly, treatment options, but genomic knowledge is also assimilated into the hopes, fears, and identities of those living with CLL.

I draw here on Couser's concept of the metaphor of the human genome as type of master text revealing aberrations and deviations which genetic medicine can read and ultimately aim to correct. "Disease/disability is cast as textual irregularity, and those in the biomedical community become editors who attempt to amend, delete, and correct the defective texts of disabled bodies" (Wilson, cited in Couser, 2004:182). Alongside acknowledgement of all the

potentially beneficial outcomes of the project, Couser also alerts us to the potential for eugenicist abuses of medical biopower. Such potential is of course undeniable, but this is not an issue generally raised in CLL community narratives. However, ambivalence to the knowledge of what is encoded into our genetic (already disclosed, or yet to be revealed) texts is a commonly encountered phenomenon in the networks. This plays out at much more than the basic level of “preferring not to know”. As yet, genetic mutations and expressions may dictate treatment and define prognosis for those with CLL, but they don’t always offer the potential of cure or agency in controlling the progression of the disease outside of the current drug regimes.

At a deeper level still, once the genetic encoding of disease is complete, it has the potential to be read as part of the essence of individual identity in which disease becomes something that can’t be attributed to your behaviour or to fate, but becomes about literally who you are at a molecular level: “This places the disease deep into the body, internally, intrinsically, essentially within” (cited in Couser, 2004:181). Couser explores the potential for this biological essentialism at once to: “stimulate and to constrain first person narratives of illness” (*ibid*). G Thomas Couser’s observations on the relationship between life-writing as both narrative and non-verbal genetic practices in an era of advancing genomic knowledge are useful to understanding how access to genetic biomarkers might impact on the way we understand and write about living with disease at a point where: “DNA itself functions as a kind of non-verbal ‘life-writing’ that is, a predictor or even ‘scripter’ of individual experience” (Couser, 2004:168). This chapter has already shown, and will continue to demonstrate how some patients at least choose to resist genetic knowledge as a potential ‘scripter’ of their lives.



## Translation: 'The Median Isn't the Message'

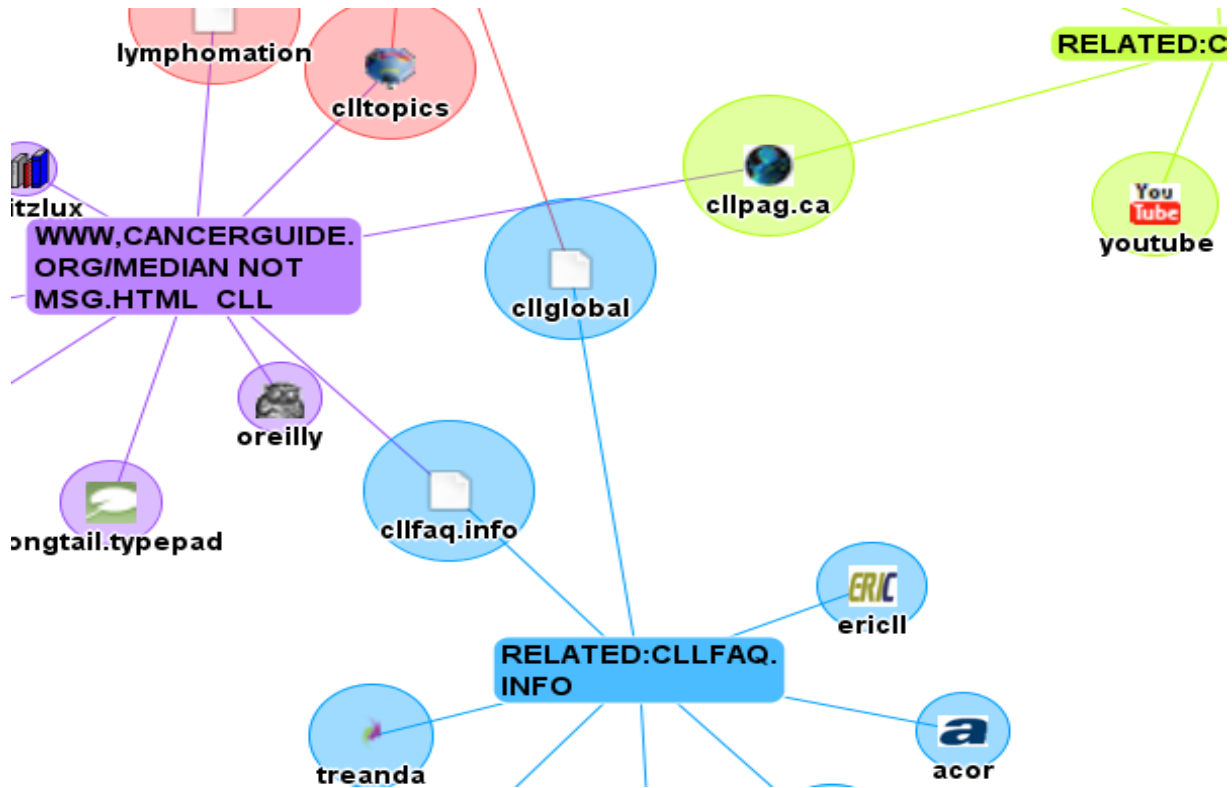


Figure 19: TOUCHGRAPH (2015) zooming in on network links for Stephen Jay Gould's paper, the Median isn't Message on [www.cancerguide.org](http://www.cancerguide.org) [Network Map]. [Online] Available at: [www.touchgraph.com](http://www.touchgraph.com) [Accessed 04/03/2015].

As the network information on prognostics in CLL we have looked at so far shows, all prognostic markers be they genetic or otherwise tend to be extrapolated to median survival curves. The following survey respondents acknowledge the resources they found useful in beginning to negotiate the slippery terrain of 'median survival':

*I was helped a lot by the discussions on the ACOR list about what "median survival" really meant, and especially by the helpful explanations of Dr. Hamblin before his untimely death. (IOB Survey Respondent 44)*

*ACOR and its archives were very helpful. Gould's essay on evaluating the stats on prognosis was a great help in gaining objectivity on my prognosis. (IOB Survey Respondent 28)*

'Gould's essay' -so instrumental in helping respondent 28 gain objectivity - refers to Harvard based evolutionary biologist Stephen Jay Gould's personal story of statistics: 'The Median Isn't the Message', written in 1982 after being diagnosed with abdominal mesothelioma and given a median survival prediction of around eight months. Suspecting (probably correctly) that most non-statisticians would interpret this as "I will probably be dead in eight months" and describing this as "the very conclusion that must be avoided, since it isn't so, and since attitude matters so much" (Gould, 1982), Gould uses statistical knowledge to demonstrate how this median statistic bears limited relevance to him as an individual. Factoring in some of the positive elements on his side such as age and early identification of the disease, natural right skewing of the data<sup>70</sup>, and the inability of fixed statistics to accommodate evolutionary shifts in treatment and survival, Gould arrives at the conclusion that there is good reason to predict that he will be in the half of the group that live longer (*median* articulating central tendency as a kind of halfway point). It could just as easily have gone the other way of course, but Gould went

<sup>70</sup> Gould reasoned that, since his disease is only identifiable at death or before, the left of the distribution contains an irrevocable lower boundary of zero. This leaves little room for the distribution's lower (or left) half, which has to be compressed between zero and eight months. But the upper (or right) half can extend out for many years prior to dying. As Gould put it: "The distribution must be right skewed, and I needed to know how long the extended tail ran - for I had already concluded that my favorable profile made me a good candidate for that part of the curve" (Gould, 1982).

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on to survive some 20 years after publishing his essay, his death the result of a secondary, unrelated cancer.

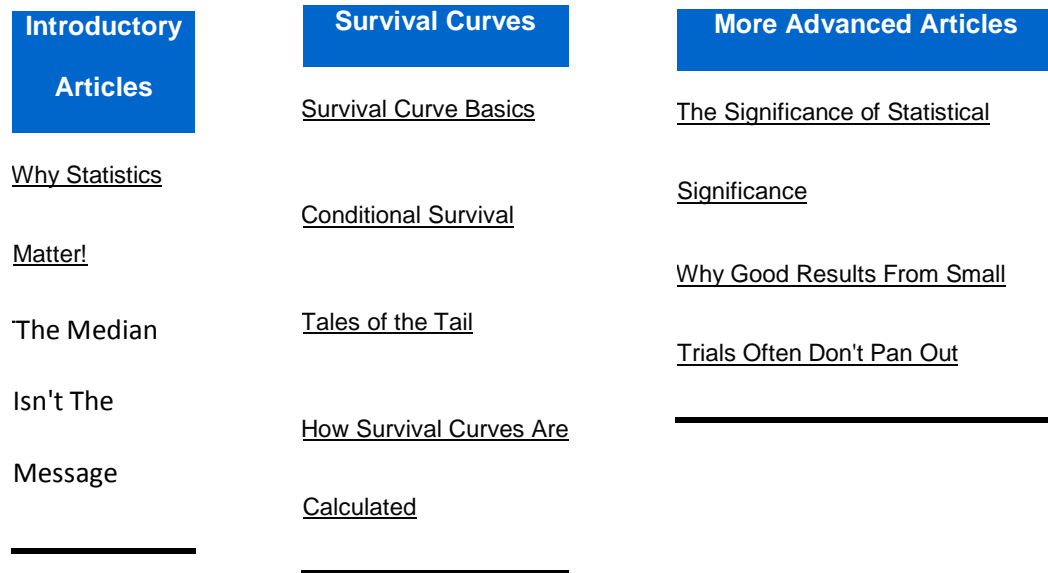
Perhaps the reason that Gould's essay still finds such a strong foothold in the networks of CLL (and other cancers) online is about more than its role as a story of hope in the face of despair and as much about its message of the empowering nature of knowledge for those whose bodies and lives have become inextricably entwined with discourses of science and risk. As Jurecic notes, the essay "draws attention to the very thing that does not interest the risk society theorists: how one man's narrative makes personal meaning of impersonal statistics" (*ibid*). The relevance of this to CLL patients is reflected in the following posting from the ACOR CLL archives in 2001 (Gould died in 2002) emphasizing his ongoing role as an active member of society with much to offer despite his initial grim prognosis, and including a link to the essay for those list members not already familiar with it:

For those who have an interest, Stephen Jay Gould (writer of the powerful words in 'The Median Isn't the Message') is apparently still doing well. I just read an article he wrote for the Times about the WTC bombing (he was also supporting the rescue efforts near Ground Zero). That would make nearly 21 years since he was diagnosed as a terminal cancer patient. For those who haven't read his inspirational words, they may be found at:

[http://www.cancerguide.org/median\\_not\\_msg.html](http://www.cancerguide.org/median_not_msg.html) (Anonymous respondent, ACOR CLL archive October, 2001).

The essay, written over 30 years ago, continues to circulate, provoke discussion, and impact on peoples' attitudes to their prognosis in very contemporary digital networks. Following the link pasted into the above posting, the reader arrives on CancerGuide's 'Statistics' page where a

copy of the essay is pasted next to a sidebar linking out to information about various aspects of understanding survival statistics organized as follows in Figure 19 below:



**Figure 20: CANCERGUIDE.ORG (2015) Sidebar from Steven Gould essay ‘The Median is not the Message’, on cancerguide.org demonstrating links out to further information about how to interpret survival statistics. [Online]. Available at: [www.cancerguide.org/median\\_not\\_msg.html](http://www.cancerguide.org/median_not_msg.html) [Accessed: 28/03/2015].**

Contextualizing the essay in this way locates it as a node in a network of supporting narratives that encourage the reader to negotiate survival statistics by building knowledge and understanding gained through a process of guided online research.

‘The Median isn’t the Message’ is a powerful circulating narrative in the CLL (and other cancer) networks. Still actively transported across sites many years after its authorship, the essay has almost cult status in cancer communities seeking as it does to “humanize statistics and also to convince readers that knowledge, in particular ‘dry academic knowledge about science’

constitutes power” (Jurecic, 2012:23). The enactments of CLL by scientific statisticians are translated from median survival predictions for patients for whom these statistics can be powerful drivers of hope or despair.

## **Perspectives: Survival Statistics and Biopower**

Such translations can underpin a counter-voice to the potential biopower inherent in the institutional use of statistical information. When Kathleen Woodward observes in ‘Statistical Panic’: “Fatally, we feel that a certain statistic, which is in fact based on an aggregate and is only a measure of probability, actually represents our very future” (Woodward, (185) cited in Jurecic, 2012: 20), she acknowledges the process by which the seemingly portentous power of medical statistics for individuals can be harnessed to exert powerful control over entire populations. This concern was obviously keenly felt by the following survey respondent:

*What concerns me is that the doctors use truth tricks to calm people who post. I find this problematic. This approach is discussed in the paper DISCIPLINING BODIES AT RISK: Cardiac Rehabilitation and the Medicalization of Fitness by Elizabeth E. Wheatley in the Journal of Sport & Social Issues, Volume 29, No. 2, May 2005, Basically, the population based data that are used in medical studies are manipulated/interpreted to meet the needs of doctors (IOB Survey Respondent 71).*

This respondent’s reference to the Wheatley paper demonstrates a desire to deconstruct statistical discourses used by the medical profession and acknowledges their potential use as a form of the biopower discussed by Woodward.

Julia Kennedy

Another approach to the potentially deleterious effects of statistical biopower (intentional or otherwise) emerged, with several respondents resisting translation of the lived reality of their disease into the predictive language of biomarkers or statistics. These patients, some with the advice of their doctors, chose instead to take feedback on disease progression directly from the body itself:

*I am not convinced that 'prognostic testing' is helpful to me. Simply put my disease behaviour over the last year is more accurate than a battery of tests (IOB Survey Respondent 254).*

*Doc said "The best indicator of how you are going to do, is how you are doing." I reluctantly accepted the doc's advise [sic] on this and as I have since become more informed about the disease, I have come to realize he is quite correct about all this. CLL TOPICS was probably the most helpful in developing my understanding of the various prognostic markers. Having now read many research articles and followed journeys of a many CLL patients who write their stories in the forums and their blogs, I have come to appreciate the limitations of the prognostic markers (IOB Survey Respondent 86).*

Again, this can be read as a resistance to accepting genetic biomarkers as pre-determined 'scripters' of individual lives (Couser, 2004:168).

Conversely however, refusal by health care providers to make prognostic information available from the point of diagnosis and throughout the disease course is perceived in itself a form of biopower by the following patient, leaving patients uninformed and unable to collaborate effectively in their own care:

*Many non-medical patients do not have a clue about the significance of the diagnosis, let alone the potential prognoses. It seems the medical profession wants to do little until the symptoms call for treatment. I have seen three consultants over the years and found all lacking in information, care concern. The first consultant, seen privately, never even told me I had CLL! I already knew, so he did not last long... Knowing your prognostic markers and the fact that they can change really is a must for all CLL patients. Surely most people want to know their future? (IOB Survey Respondent 169)*

The right to accurate personal predictive markers notwithstanding, ‘The Median isn’t the Message’ positions us to consider how people might: “make the mistake of living their lives by the numbers instead of attending to the dissonance between those numbers and their experiences” (Woodward, [185] cited in Jurecic, 2012: 20). Evidence in the CLL networks shows that people are very aware of this dissonance, although learning to meaningfully relate one’s lived reality to prognostic predictions is a process that takes time and understanding. This understanding incorporates awareness of the heterogeneous nature of the disease itself, differentiation between prognostic and predictive markers (and the evolving role of biomarkers in personalized approaches to care), and acknowledgement of the limitations for individual cases of generic statistical evidence. Again, it becomes clear that the networks themselves play a significant role in this educational process through exchange of knowledge and personal narratives:

*CLL Topics gave me clear information on the test and prognosis backed up by lots of clinical trials, so I was not receiving conflicting information from any blog sites. What CLL Topics print is backed up by clinical trials or test so I feel I can trust it and it has proved to be the case so far (IOB Survey Respondent 179).*

Managing the desire to personalize the impersonal language of prognostics is part of the process of coming to terms with the prospect of a shortened lifespan for anyone struggling to accommodate the impact of diagnosis with a life-threatening disease on their sense of self. Jurecic claims that few patients have the conceptual, linguistic, narrative, and statistical resources required to underpin “the confidence and knowledge necessary to quickly recast a sense of self in relation to a new and threatening prognosis” (Jurecic, 2012:22). This view is shared by the following respondent’s belief that most patients seek to interpret survival statistics within frameworks of a strong sense of optimism for their own circumstances rather than attempting to gain a realistic outlook:

*Discussion of prognosis comes up frequently at all sites and at all meetings. However, few people understand anything about statistics and certainly not how they apply to the individual. People always think that they are on the right hand side (the survival part) of the curve. However good your prognosis, it is only an indication. I feel that when people are asking for prognostic factors what we are really asking for is to be told that 'hey, it was a mistake, you are going to live forever'. It is human, and adds to the feeling that you are in control... (IOB Survey Respondent 168)*

There is a very real possibility of course that being given a poor prognosis will have a chilling effect on the quality of a patient’s remaining life, as previously cited respondents have concurred. I am not certain though that it is possible to polarize the effects of knowing to *either* power *or* cruelty. Nor am I convinced from the data gathered in this study that people are entirely lacking in the resources to quickly recast a sense of self in relation to a challenging prognosis as suggested by Jurecic, but perhaps this is where chronic cancers become distinct from their more aggressive counterparts. Evidence of people coming to terms with their CLL



prognosis over time, assisted through assimilation of the narratives of others in the networks is strong, and it is certainly the case that a slow growing malignancy offers its host more time to navigate its potential impact on their sense of self and future. When one is very often facing median survival times of years rather than months or weeks, the need for a very rapid recasting of self is to some extent ameliorated. It needs to be stated however that *any* prognosis with an incurable malignancy, particularly one such as CLL that significantly increases the risk of secondary malignancies, requires significant work in re-articulating the self as the previous chapter has shown.

In truth it seems one must be prepared for the fact that power and cruelty may be at times be intimate bedfellows in relation to prognostic knowledge, and indeed that power itself in this context might not always be about the ability to beat the odds, but might just as easily be defined as learning to live (or die) well in the face of them, as the following respondent indicates:

*Having both "good" and "bad" markers did not help with clear conclusion. Eventually, I stopped giving them much thought. My challenge was to learn to live with CLL, making the most of whatever time I have without letting CLL hijack my life (IOB Survey Respondent 71).*

For someone managing to retain relatively good health and quality of life in the face of the disease, time not only allows for, but to a large extent *demand*s this process of 'learning to live with' a life-threatening illness. Life goes on, threatened by a compromised immune system, possibly significantly curtailed in terms of its expected span and, for some, in terms of its day to

day potential, but intrinsically live-able in the here and now. As the above respondent declares, learning to live as 'normal' a life as possible, despite the impossibility of knowing how long that remaining life will pan out post diagnosis, like a skill, is something that has to be learned over time.

### **Perspectives: Re-skilling in Risky Bodies**

Elizabeth Wheatley, in her 2006 ethnography of heart disease, refers to the process of *reskilling* undertaken by people after acute episodes of cardiac disease. Drawing on Anthony Giddens' (1991) views of the self as a 'reflexive project' organized around responses to risk in late modern life, Wheatley focuses particularly on the 'fateful moment' as a galvanizing factor for reskilling work. Described by Giddens as a point 'where a person learns of information with fateful consequences' (Giddens, 1991: 113), the fateful moment requires decisions or actions that essentially recast a life course or narrative. Locating the cardiac event as such a fateful moment, Wheatley describes the process of reskilling as an ongoing effort to "interpret risks and remake the body, to redefine and reinvent the self, and to rearrange social relations and routines" (Wheatley, 2006: 3). For a progressive disease such as CLL, the initial 'moment' of diagnosis and subsequent moments of prognosis, treatment, remission and relapse can readily be interpreted in this model whereby constant re-skilling is required throughout each phase.

Not everybody diagnosed with this heterogeneous condition however benefits from the advantages of time and relative good health to smooth the reskilling process. The survey yielded a jarring response from a wife whose husband's rapidly declining health, and limited survival time after commencing treatment came as a cruel shock to them. This was compounded by learning too late from a pre-treatment FISH test of the presence of a 17p deletion, indicating poor response to therapy. Having to wait until treatment is required for this test means that poor prognostic or challenging predictive indicators remain unknown to many patients and their medical teams throughout their watch and wait period:

*Had we had prognostic tests done at the beginning, I would have retired and we would have done some traveling while my husband was in watch & wait. Traveling was always a joy and we intended to do it in retirement - with an RV. By the time we got to an expert and heard the bad news of 17p he was too ill to travel and never regained health. I encourage people to have it done if they happen to be going to a local hem/onc who doesn't do it - as I encourage them to see CLL experts - as I shall always regret that we were uninformed until it was too late. And becoming informed was totally the result of CLLTopics.org. The support group ACOR was helpful once we became educated about the disease (IOB Survey Respondent 42).*

As novel treatments begin slowly to roll out into clinical trials and use, the outlook for patients with a 17p deletion is improving. At the time of the respondent's experience, viable options to chemotherapy to which this group respond so poorly were virtually non-existent. The sense here then is not so much that knowledge would have changed the course of the disease itself, but that it would have inspired a different approach to living what life was left. In hindsight, this respondent sees a cruelty in the *lack* of knowledge of her late husband's poor prognosis, translated into opportunities to seize the moment now forever lost.

## **Perspectives: The Fateful Moment and the New Digital Expert**

Giddens points out the important role of the ‘expert’ for anyone confronting one of life’s fateful moments. “Experts are often brought in as a ... fateful decision has to be taken ... knowing that a decision made or a course of action followed has an irreversible quality” (Giddens, 1991:114).

The role of the expert is writ large across the previously explored posting of respondent 42, and a very clear distinction is made between ‘CLL experts’ and local more generalized haematologist/oncologists (haem/onc), treating a broad range of heamatological conditions out of local hospitals. For this respondent, her husband *not* being treated by a dedicated CLL expert translated into them remaining ‘uninformed until it was too late’. Their decision to wait until retirement to realize their travel plans (rendered irreversible when death intervened) was made in the absence of prognostic/predictive information that the respondent feels would have been available to them had her husband been under the care of a dedicated CLL specialist. We learn that the knowledge and support they were eventually exposed to, giving them the confidence and resources to seek out a CLL expert, came about directly through engagement with online networks, CLL topics and the ACOR list, both of which are identified as major nodes in the network map for this chapter. As addressed in the introduction, the informed ‘e’ patient (or ‘e’-carer) is an auto-didact, learning to negotiate the networks in order to build the knowledge required to actively participate in online debate in relation to their disease.

For patients in a digital era, Giddens’ notion of the ‘expert’, sought out at fateful moments, just as likely to be an online physician, scientist, another patient, or the self – educated by exposure

to a range of online expertise. As we have also seen, however patients in the network go about achieving their own level of understanding and expertise, it increasingly translates to the clinical relationship in the consulting room. Those patients and carers negotiating the networks of knowledge exchange online require expertise from their clinicians. If they perceive that they are not getting that, some actively seek second opinions or even alternative clinicians, whilst others choose to use what they find online to negotiate with their clinicians:

*My doc did not do prognostic testing and I had to push for it. CLL Canada is wonderful and nicely organized (IOB Survey Respondent 64).*

Such negotiations require clinicians confident and willing to work *with* their patients in a collaborative relationship that allows for discussion of the knowledge gleaned online. This is knowledge that in many cases general haem/oncs have not had the opportunity nor time to consider in as much detail as their patients, who have the time and motivation to benefit from daily exposure to global discussion of the very latest research and shared experience of their disease should they choose to engage with the networks at that level.

Thus far, the chapter has demonstrated how patients begin to negotiate the gap between prognostic indicators as tools for predicting their likely lifespan, and as predictors of potential disease courses. Although distinctions still tend to get made in terms of median survival times according to CLL 'type', patients engaging with prognostic information often see beyond the statistics to seek the frameworks for *informed* predictive planning, seeking out appropriate

trials, being able to discuss potential treatments with Doctors, making decisions about work and family life and so on.

This section will look at three sites or nodes, operating in the CLL networks at the time of research, and tracing some of the key prognostic issues across them, in particular the relevance of IVGH mutational status.

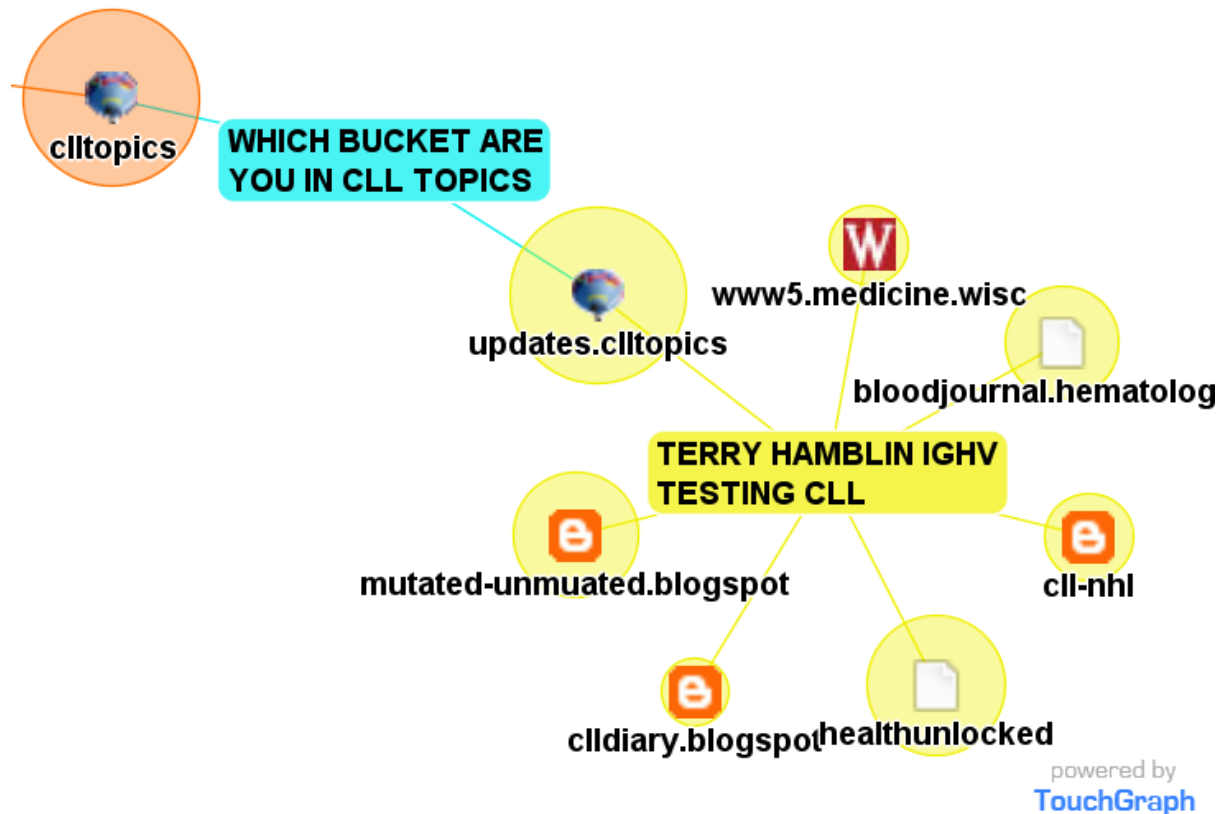


Figure 21: TOUCHGRAPH (2015) zooming into networks to look at links between CLL Topics, Mutations of Mortality Blog and Patient Discussion on CLLSA Health Unlocked [Network Map]. [Online] Available at: [www.touchgraph.com](http://www.touchgraph.com) [Accessed 04/03/2015].

The first two sites I look at are Chaya Venkat's CLL Topics, particularly her (2010) page 'What Type of CLL do you Have?', and Dr, Terry Hamblin's Blog 'Mutations of Mortality', particularly his entry from Tuesday, May 08, 2007: 'Why should I get my prognostic markers done???' <sup>71</sup>

Although still available for viewing, both sites now lie dormant, following the retirement in 2012 of Chaya Venkat, CLL Topics' founder and author, and the death of Terry Hamblin in 2013, they were selected on the basis of their significant function and popularity as key actors in the networks during the fieldwork period, as evidenced by the following survey responses:

*My prognosis was - and still is - mixed. The more I learned, the more I realized the research in this area is still far too new to be more than vague guidelines for most of us. Chaya's "Which Bucket Are You In?" is still the best word on the subject (IOB Survey Respondent 54).*

*CLL Topics is where I found most of my information early on. Very helpful. Online I was able to discuss with Dr. Hamblin specific markers. I know I would not have been able to do so without the internet (IOB Survey Respondent 116).*

*CLLtopics. Period. The best and most informative. Susan LeClair interviews always are clear and in simple language. I love her for that single fact. CLL Global Research. CLL/SLL@yahoo.com Lastly, I loved Dr. Hamblin's (CLL doc. in Bournemouth) blog until he passed from an unrelated cancer. NIH for clinical trials (IOB Survey Respondent 30).*

*Via CLL Topics and the ACOR list I learned of a study at the NIH and entered the study in order to access expert opinion and prognostic testing, as well as contribute to the current body of knowledge re untreated CLL (IOB Survey Respondent 121).*

<sup>71</sup> <http://mutated-unmuated.blogspot.co.uk/2007/05/why-should-i-get-my-prognostic-markers.html>

Julia Kennedy

In addition, I'll look at an online discussion prior to treatment on the CLLSA Health Unlocked site concerning the availability of IVGH mutational testing in the UK, picking up the same subject and bringing it more up to date in an online patient community discussion.

This tripartite approach allows me to map information exchange across three distinct nodal forms. Firstly, in CLL topics, a site in which complex information relevant to CLL prognostics has been gathered, collated and translated for a lay audience by a scientist. Secondly, Terry Hamblin's Mutations of Mortality demonstrates a similar process of translation undertaken by a CLL specialist but presented in a more open and discursive blog format. Finally, I trace the debate into a patient-led CLL community following the discussion 'Who is Getting the IGHV (formerly known as IgVH) Mutational Status Tests in UK?'

### **Translations: 'Which Bucket are you in?' (A Scientist's Enactment)**

On January 1<sup>st</sup>, 2010, Chaya Venkat posted her much-visited page 'What type of CLL Do you Have?' on her site CLL Topics. Drawing on seminal papers in the history of CLL research, it amounts to a 6,500 word essay on current diagnostics and their relevance to the CLL community. Making the point that CLL runs many different courses with significantly different outcomes, Venkat reminds readers that:

The spectrum stretches all the way from a 'good' cancer that is not going to do much of anything for the rest of your normal life span to an aggressive, incurable cancer that requires treatment soon after diagnosis, compromise your quality of life with frequent



infections and ultimately kills you in a few short years. (Venkat, 2010)

This chapter has so far demonstrated the ambivalence, inconsistencies, and sometimes confusion surrounding prognostic information that exists among CLL patients. Venkat is stark however in her view of the potential implications of a lack of prognostic knowledge for the CLL patient when she warns readers against a ‘head-in-the-sand’ approach to their diagnosis. ‘What you don’t know about CLL can literally kill you a lot sooner than otherwise. How is that for motivating you to find out more about your particular brand of CLL?’ (Venkat, 2010)

Sorting CLL patients into what she calls ‘risk buckets’ according to various prognostic indicators, all contextualized by the research and clinical perspectives that underpin them, Venkat gives advice to each group on how to manage their particular ‘type’ of CLL. These are summarized in the following table (Figure 21) reproduced from the site:

Table removed due to copyright restrictions

**Figure 22: VENKAT, C. (2010) The Bucket Brigade [Table] from 'What Type of CLL Do You Have?' CLL Topics. [Online] January, 1st. Available at: <http://clltopics.org/PI/Type.htm> [Accessed: 14.12.2013].**

Acknowledging that very few people are likely to have a disease pattern that lines up all of the markers as neatly as the table does, Venkat offers the summary as a tool for providing baseline information within which patients might usefully locate their own individual experiences.

Across the networks however, one particular prognostic indicator currently stands out as a consistent indicator of likely outcome, and that is what is known as a patient's IVGH (ImmunoGlobin, Variable region, Heavy chain) mutational status<sup>72</sup>.

In 'Which Bucket Are You In?', Venkat points out that, unlike many other biomarkers that evolve with time, IVGH mutational status remains consistent across the lifetime of a patient and, along with FISH status, is 'probably the single most important prognostic test' (Venkat, 2010). Venkat's web-essay refers to 'Unmutated IgVH Genes Are Associated With a More Aggressive Form of CLL', a paper by Terry Hamblin in *Blood* journal, from which she replicates a graph indicating median survival times for patients in either the 'mutated' or 'unmutated' groups. Neither author leaves the reader in any doubt as to the dramatic difference in outlook for the two groups:

Median survival for unmutated IgVH CLL: 95 months.

Median survival for mutated IgVH CLL: 293 months (Venkat, 2010).

<sup>72</sup> IVGH was originally referred to as IgVH. CLL patients form 2 broad groups based on the mutational status of the immunoglobulin heavy-chain variable-region (IgVH) gene in leukemic cells, those with IgVH gene mutations generally surviving longer than those without. For that reason, it is thought that mutation analysis may be a valuable indicator for planning care management strategies. Two potential surrogate markers, CD38 and ZAP-70, received significant focus due to their association with lack of IgVH mutation, but it has not proved possible to evidence 100% correlation (Quest Diagnostics, no date)

Julia Kennedy

That represents a median survival difference of between around eight and twenty-five years respectively for the unmutated and mutated groups as shown on Hamblin et al.'s graph in Figure 22 (below).

Graph removed due to copyright restrictions

**Figure 23: HAMBLIN, T. (1999) Unmutated IgVH Genes Are Associated With a More Aggressive Form of CLL [Graph]. From VENKAT, C. (2010) 'What Type of CLL Do You Have?' CLL Topics. [Online] January, 1st. Available at: <http://clltopics.org/PI/Type.htm> [Accessed: 14/12/2013].**

Before moving on to Terry Hamblin's own blog to take a closer look at the source of his paper cited here translated in a different nodal context, there are two further features of the CLL Topics page worth drawing attention to.

Firstly, Chaya Venkat's evident skill and patience in translating complex science for a lay audience seems to be at the heart of CLL Topics taking the highest popularity ranking for sites visited regularly among the survey respondents (68% said they used CLL topics regularly, with the ACOR CLL list being its closest competitor at 44%). Using familial metaphor, she sets about explaining mutational status and its potential impacts in a way that allows patients to relate median survival times to a comprehensible narrative of cell biology. Referring to the very first malignant B-cell that marks the genesis of CLL in a patient as the 'patriarch of the CLL clonal family', the malignant cell that produces all the rest, Venkat explains how IgVH mutation status stands in for the precise point in the cell's lifecycle that it became malignant:

'In some patients, this patriarch of the CLL clonal family became a malignant cell before it finished its "education" in the germinal center. This "ignorance" of the first CLL cell is reflected in the immunoglobulin (Ig) of the cell being unchanged. .. Since this first cell eventually gave rise to all the other cells in the CLL clonal family, all of the CLL cells in these patients have unchanged or "unmutated" Ig. The mutation of interest is in the heavy chain of the Ig, in the variable region. Put all that together, and we come up with unmutated IgVH (immunoglobulin, variable region, heavy chain)...In other patients, their very first CLL cell became a cancer cell after its trip to the germinal center. In these patients, since the first cell had graduated from the germinal center, the IgVH of this first CLL cell has been changed, ("mutated"), and this trait is carried forward by all the off-spring of this first cell. These patients have "mutated" IgVH (Venkat, 2010).

Translating cell biology in this way for the reader, Venkat mediates information from its research sources in the form of Hamblin's paper to the lives of those reading her web page. It is as if she says to the reader 'Look at the graphs, consider the figures, understand the science, and think about what it means to you in the context of your own disease'. She doesn't stop there though, and this is where the second point of interest occurs.

Julia Kennedy

Writing from the position of someone who has herself lost a loved one to CLL, Venkat works not only to translate and mediate information, but to *actively* encourage patients to use the information in the context of the clinical setting and, in doing so, to become their own advocates in a collaborative clinical relationship. In the case of IgVH status testing, she acknowledges a lack of consistency in general oncologists' knowledge of and attitudes to the test, and encourages patients to negotiate access to it in a broader model of patient-led empowerment:

Not all local oncologists are familiar with the IgVH status test and you may have to do a bit of sweet-talking to get your guy to write a script for it. What you get in life depends to a great deal on your ability to negotiate with other people and getting effective medical care is no different (Venkat, 2010).

I will return in this work to the issue of organized online advocacy in the Treatment chapter, but want to look now at Terry Hamblin's blog posting on Prognostic Markers as a differently formatted approach to professional sharing information with patients online.

### **Translation: 'Why Should I Get My Prognostic Markers Done?' (Ask the Specialist)**

A CLL specialist at Bournemouth Hospital from 1974-2003, Terry Hamblin set up his blog Mutations of Mortality, subtitled 'Random thoughts of Terry Hamblin about leukaemia, literature, poetry, politics, religion, cricket and music' in 2005. 'Mutations of Mortality' was cited by many survey respondents as a trusted online resource, and the blog exhibits strong links into many online CLL forums prior to his death and beyond.

Julia Kennedy

His entry of Tuesday, May 08, 2007 is entitled 'Why should I get my prognostic markers done?', and is an excellent example of one of a number of CLL specialist clinicians voluntarily taking up a place in the networks, translating clinical information for online patients and sharing ownership of medical in ways redolent of new models of digital healthcare referred to by Tom Ferguson in his e-patient 'white paper' of 2010.

Hamblin starts the entry by acknowledging the differing approaches to a desire for prognostic knowledge among CLL patients, reflected in the IOB survey responses:

Your disease will either progress or not, and when and if it does progress there is time enough to consider treatment, but until it does you might as well forget about it. Undoubtedly, some patients are able to put it out of their minds. On the other hand some patients are happier if they can know all there is to know about their disease, be it good news or bad (Hamblin, 2007).

Hamblin takes a more sanguine and fatalistic approach to the value of prognostic knowledge seeking than Chaya Venkat with her rallying call for prognostic self-advocacy as a potential lifesaver. Written eight years before the completion of this PhD thesis, Hamblin is writing prior to the widespread recognition of the increasing importance of *predictive* markers in the context of evolving treatment approaches (demonstrating just how rapidly CLL knowledge advances). The narrative of 'Mutations of Mortality' ended with the death of its author in 2012, and so we are looking here at a very particular moment of CLL history frozen in time. Cutting edge in 2007, inevitably it lags behind evolutionary changes in 2015, yet its sentiments are still echoed by some patients and their doctors. My own consultant remains unconvinced of the value of IVGH

testing outside of trials for example, as do many others in the UK. Seven years may be long enough to shift the paradigms of treatment and disease knowledge on their axis, yet not long enough to make those new treatments universally accessible, nor to shift the cultural attitudes to prognostic testing shaped by the previous decade of treatments and biological understanding.

However, Hamblin's blog entry remains a powerful example of several forms of translation. I have already mentioned that of 'expert' knowledge into the CLL networks for patients. I would also draw attention to the ways in which Hamblin situates his views in a history of prognostic knowledge in CLL by taking readers back to what he refers to as 'the beginning', a time before any prognostic markers were available and patients were classified using either the Rai (American) or Binet (European) systems according to stage. Hamblin locates these staging systems in a time prior to another fundamental shift in the understanding of CLL, one that he himself contributed significantly to as we have already seen from the CLL Topics site. The differentiation between the two forms of VH gene mutational status in 1999 smashed traditional understanding of CLL as a singular disease operating on a continuum with totally arbitrary points and rates of progression. Referring to two seminal papers in the history of CLL knowledge appearing in *Blood* in 1999, Hamblin et al. (his own work), and Damle et al., he explains how a new understanding of CLL as two *distinct* diseases according to mutational status emerged:

Far from being a marker of prognosis, to know your VH gene mutational status was part of the diagnostic procedure; did you have this type of CLL or that type? It was as



important as knowing whether you had follicular lymphoma or diffuse large cell lymphoma (Hamblin, 2007).

More changes were in the prognostic pipeline at the time that would complicate this binary view of CLL. Hamblin refers the blog reader to a paper published in 2000 in *the New England Journal of Medicine* by Dohner et al. exploring the use of FISH testing for chromosomal abnormalities as a prognostic factor. Now a standard part of pre-treatment prognostication, Hamblin's historical overview also draws attention to the broader networks in which scientific discovery is translated into clinical action. By informing readers of a paper on the same subject of chromosomal abnormalities published in the same journal some ten years earlier than the Dohner paper by Juliusson et al (1990), Hamblin makes the blog reader aware of the role of laboratory assays in the understanding of their disease. In 1990, Hamblin tells us that 'the technique of karyotyping was unsuccessful in most laboratories' (Hamblin, 2007). Juliusson et al may have come up with the goods about the importance of chromosomal testing, but laboratory technology was as yet unable to translate that into clinical practice. A decade on, FISH testing enabled easy and reproducible laboratory detection of four of the most common chromosomal abnormalities (trisomy 12 and deletions on chromosomes 11, 13 and 17), and FISH testing becomes a recognizable part of every CLL patient requiring treatment's journey.

Julia Kennedy

In an updated entry on the subject in 2010, Hamblin describes how the optimism for Zap-70<sup>73</sup>, as a reliable prognostic indicator was similarly undermined by difficulties faced with commercial assay techniques:

The trouble with ZAP-70 is finding a method that everyone can agree on. The concordance with IgVH mutations was over 90% using the first two published methods, but only 76% when the method developed in Tom Kipps lab was used. That paper suggested that it was a better prognosticator than IgVH mutations, but when it was adopted by commercial labs, very strange results indeed were apparent (Hamblin, 2010).

Through engaging with the blog, CLL patients begin to get a sense of how their personal disease narratives intersect with multiple histories, narratives and disciplines. Advances in prognostic testing can succeed or fail on the basis of the laboratory technologies and economies that enable it, and the potential impact of that on the lives of those living with CLL is significant. For those patients who wish to understand how they are situated in the broader networks of CLL enactments (and perhaps go on to advocate or campaign for changes in specific areas of care), this 'bigger picture' knowledge is helpful.

The blog entry goes on to update current information on VH genes and chromosomal abnormalities in relation to relevant clinical experience and trial results, and Hamblin closes the entry by returning to his observations on the different attitudes patients may take towards

<sup>73</sup> Zap-70 is a tyrosine kinase and crucial molecule for the selective activation of T cells. It is used in the transmission of signals from the T-cell receptor to downstream pathways. B cells generally lack ZAP-70, using related tyrosine kinase, Syk, instead. In most cases of CLL with mutated IgVH genes, stimulation of the B cell receptor fails to cause a signal to get through, although most cases with unmutated IgVH genes signal satisfactorily (Hamblin, 2006)

prognostic information, but stating clearly that those who want it should have access to it. “As I said, some patients relish this sort of information; some disdain it. I am not going to judge between them. However, I think that everybody should be able to access it if they want it” (Hamblin, 2007).

Six patients posted responses to the blog, Hamblin responding to each in turn. Questions were largely seeking clarity around the statistical implications of Hamblin’s own work on mutational status, indicating a desire from the questioner to locate the narrative of their own disease within the inferences of the research. As one of the blog respondents put it: ‘I am one of those who relish knowing all the numbers’.

During Terry Hamblin’s life, ‘Mutations of Mortality’ came to represent a powerful node in the CLL networks. Linked into a range of other popular sites such as CLL Topics and often referred to in forums and listservs such as ACOR, Hamblin’s status as a CLL expert willing to share information with a largely lay audience of CLL patients, and to interact with them personally secured his status as an important mediator of clinical CLL information and opinion, and a key network actor. Through Hamblin’s online hypertextual presence, the networked patient had access to a degree of specialist consultation. No amount of informal online contact with a doctor can wholly *substitute* a patient’s own relationship with their doctor, but there is little doubt that the ability to ask specific questions about and gain a broader specialist understanding of their disease outside of the clinical setting can impact significantly on the conversations and decisions taking place within it, as 79% of IOB survey respondents indicated.

In reading and interacting with ‘Why should I get my prognostic markers done?’, CLL patients get an expert answer to that vexed question that is both broadly contextualized, contemporary at the point of publication, ongoing (until the author’s death ) and personalized if required through the interactive potential of the blog format.

### **Translations: ‘Who is Getting IGHV test?’ (Ask the Community)**

In September, 2013, experiencing sudden aggressive disease progression and facing treatment with chemoimmunotherapy, I became concerned that I didn’t know my mutational status despite having read a great deal about its relevance to outcomes. As the previous section has shown, mutational status is widely acknowledged to be a reliable prognostic indicator, those patients testing positive for IGHV status currently having more favorable outcomes on the whole. Despite its prognostic value, mutational status does not currently dictate or influence treatment protocols and as such is regarded as a superfluous test by many hospitals. With the IVGH mutational test not routinely available at my own hospital, and obliged to wait until I needed treatment for cytogenetic testing, I decided to solicit advice directly through the online support networks, actively seeking to negotiate the dissonance between what I was reading and learning online, and what I was experiencing in the context of the management of my own disease by drawing on the experiences and views of others. Figure 23 shows the artwork, *Laksmi in the Blood* by Paul Heussenstamm that I use as my avatar alongside my username Jibs60 on the CLLSA Health Unlocked site.

Image removed due to copyright restrictions

**Figure 24: HEUSSENSTAMM, P. (No date) Laksmi in the Blood Stream [painting] used by Jibs60 as an avatar on CLLSA HealthUnlocked [Online]. Available at: [http://www.mandalas.com/mandala/htdocs/Agape\\_Show/Laksmi\\_in\\_the\\_Blood\\_Stream](http://www.mandalas.com/mandala/htdocs/Agape_Show/Laksmi_in_the_Blood_Stream) [Accessed 12/06/2013].**

I turned in the first instance to the CLLSA UK forum hosted by the HealthUnlocked platform, and posted the question ‘Who is Getting the IGHV (formerly known as IgVH) Mutational Status Tests in UK?’, articulating my desire for further information as follows:

As IGHV mutational status is acknowledged to be a good indicator of likely response to FCR treatment, including potential clonal evolution, I'd quite like to have the test done now as I approach treatment. It would be useful though to get an idea of what is going on at other hospitals in relation to this test prior to treatment and outside of trials. I gather the test is not cheap, and want to make an informed decision about whether I should be requesting it based on the experiences of others in a similar situation here in the UK. (Jibs60, 2013)

The question received 13 detailed and informed responses sharing personal experience and links out to research papers and other sources of information in the networks. I was interested in ascertaining who was getting the test in the UK, whether those accessing it had found it useful, and which UK centres offered the test. I also wanted to know if others in the community had found a correlation between their CD38 and IGHV mutational status<sup>74</sup>. This issue was regularly addressed in various CLL forums at the time, and in my post I referred to my own negative CD38 expression shown in the lab report from my immunophenotyping (replicated in Figure 24 below), in relation to a quote from a recent discussion thread on the site:

If your CD38 is under 30% your IGHV gene is likely mutated. If the percent is over 30% the gene is likely unmutated. This CD38 is called a marker and is about 70% correct. Further, the percent changes over time, but rarely goes over or under the 30% mark' (Anonymous response, 2013).

I recently got my FISH results back and had for some reason assumed that I would also get IGHV mutational status tested along with that as part of pre-treatment diagnostics. However, my consultant pointed that was not done as routine at my (non CLL specialist centre) hospital. My CD38 was marked simply as NEGATIVE on my flow cytometry report taken on diagnosis, so the assumption would be that I am likely mutated using that as a surrogate test (Jibs60, 2013).

<sup>74</sup> For a while, alongside ZAP-70 its expression was viewed as an effective surrogate for the information provided by VH genes and many patients turned to the CD38 expression indicated by their initial flow cytometry read-outs performed on diagnosis in order to second-guess their vh mutational status.

CD19	94	%	
CD20	89		
CD23	92	%	(0-100)
CD25	64	%	(0-100)
CD25 Staining intensity		Weak	
<u>CD38</u>		NEGATIVE	
CD79B	76	%	(0-100)
CD79B staining intensity		Weak	
CD103		NEGATIVE	
CD5+CD19	94	%	(0-100)
FMC7	50	%	(0-100)
Kappa	<1	%	(0-100)
Lambda	89	%	(0-100)
SIG Staining intensity		<u>Weak</u>	

**Figure 25: RCHT (2011) CD38 Negative status indicated on my own immunophenotyping panel following diagnostic flow cytometry in March, 2011 [Lab Report].**

Having read Terry Hamblin's Mutations of Mortality blog entry on prognostication previously, I also drew attention to his scepticism around the usefulness of CD38 as a stable surrogate marker:

I know that some specialists, the late Terry Hamblin included, felt that the surrogate test provided by CD38 was unreliable due to its tendency to change over time, whereas IGHV remains constant (*ibid*).

The following quote from Hamblin's blog indicates his position on the usefulness of markers CD38 and Zap-70. Both were initially seen as useful additions to the

prognostic toolkit before gradually falling out of favour, CD38 because of its propensity to change over time, and Zap-70 because of the lack of an effective standardized assay:

CD38 and ZAP-70 started out as quick and easy ways to get the same information as the VH gene mutations, but both have proved to be unsatisfactory surrogates (Hamblin, 2007).

Among the 13 responses was a customarily information-rich response from Hairbear:



HAIRBEAR CLL SUPPORT ASSOCIATION

The Cardiff group published a definitive prognostics paper last year that was the result of a very large UK study...

**Defining the prognosis of early stage chronic lymphocytic leukaemia patients.**

[www.ncbi.nlm.nih.gov/pubmed...](http://www.ncbi.nlm.nih.gov/pubmed...)

Excerpt from abstract;

*" IGHV mutation status, CD38 and age at diagnosis were independent prognostic variables for TTFT and OS. Therefore, IGHV mutation status and CD38 expression have independent prognostic value in early stage CLL and should be performed as part of the*



*routine diagnostic workup. ZAP-70 expression and FISH were not independent prognostic markers in early stage disease and can be omitted at diagnosis but FISH analysis should be undertaken at disease progression to direct treatment strategy.”*

The paper has been discussed by Chaya at CLL topics where the significance of IGHV is also focused upon.

[updates.clitopics.org/4336-...](http://updates.clitopics.org/4336-...)

From a patient perspective I can understand thoughts ahead of treatment with FCR if recent data published at ASH by Anderson are suggesting that those who gain best results are mutated?? (Hairbear, 2013b)

Hairbear’s detailed response to my question, which draws in the first instance on expert circulating narratives online, demonstrates how online information from the CLL networks finds its way into the conversations of CLL patients online in reference to their own individual experiences. In turn, the reading and archiving of such conversations by fellow members forms a continual pedagogic backdrop to online community activity that fits Tom Ferguson’s model of online ‘patient-helpers’ (Ferguson 2012: 1129) as valuable resources for others with the same condition. As the knowledge gained finds its way back into the clinical setting, we also become potential allies for health professionals. However, it is important to note that local care protocols and resourcing issues mean that patients in the network may have very different experiences of actually *effecting* any change in their own treatment with the knowledge they bring from the networks into their own specific clinical setting. As one member pointed out in a response to this question, “Well since I have had a Richter's transformation there is a 68% chance that I'm IGHV4-39, type 8...Absolutely nothing could change it...you play the cards you were given” (Anonymous, 2013).

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However, there is some evidence that knowing one's mutational status becomes increasingly more useful information in relation to prognostic outcomes, as indicated in my response:

I agree with \*\*\*\*\* that we play the cards we are dealt, and there is nothing we can do to change the deal. Playing 'blind' though makes it very hard to plan strategically for an increasingly complex treatment future. Knowing which mutational status card I hold could have an impact on my decision about whether to go with FCR now or to try and wait for a chance at ibrutinib next year... (Jibs60, 2013).

Some contributors to the thread supported a desire for testing, whilst others cautioned from personal experience against a) the inability of markers to predict future clonal evolution, and b) the difficulty of dealing with an unmutated status should that be the outcome of a test. Yet another response outlined a similar cautionary tale of having an unmutated status in contradiction of very low CD38 expression. This state of 'informed uncertainty' is a common theme in networked CLL patients, again reflecting some of the gaps and inconsistencies in evolving knowledge. The sometimes worrying confusion this causes is well articulated by the following IOB survey respondent:

*...the prognostic indicators are not decisive enough to the newly diagnosed as I am. I tested 10% CD38 which implies I have a high chance of having mutated CLL yet my IVHG results came back as unmutated which I understand is the definitive [sic] test at this time. it just causes unnecessary[sic] stress. It's time to scrap unreliable indicators or at least waving them in the faces of patients who are scared anyway (IOB Survey Respondent 145).*

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An inconsistency in approaches to prognostic testing is clearly articulated across the network with variations between US, UK, Australian and Canadian hospitals at both national and local levels recounted in the feedback. This UK respondent expresses surprise that not all patients are offered prognostic testing as routine at diagnosis:

*Tests for all prognostic markers at time of diagnosis were made available to me and duly carried out. I assumed this to be normal for all patients diagnosed with CLL - I now know this not to be the case, but very much depends on where you live and whether you have access to a hospital with a specialised haematology department (IOB Survey Respondent 210).*

To this date, even following treatment with FCR after my disease took an aggressive turn in 2013, I remain unaware of my mutational status. This despite consistent acknowledgement in the CLL literature that mutational status is a reliable prognostic indicator with use value in planning treatment strategies:

Several multivariate analyses have confirmed unmutated IgVH to be an independent adverse prognostic marker in patients with CLL. The presence of unmutated IgVH is strongly associated with poor-risk genomic aberrations and overexpression of CD38 and ZAP-70. Nevertheless, these associations are not absolute. The design of future clinical trials are already incorporating novel prognostic markers such as IgVH, among others, as part of risk-adapted strategies aimed at improving treatment outcomes by tailoring the aggressiveness of the therapy proportional to disease risk (Kharfan-Dabaja et al: 897).

Thus far in the UK, if you are treated at a research centre, by a CLL specialist, or are in a trial, you may benefit from this. Otherwise, treatment will be planned and administered regardless of mutational status, and any potential difference it might make.

## Chapter Summary

Through a mapping of a variety of online resources, survey responses, and broader contexts of prognostic testing in CLL, from the ability of laboratory assays to translate research into clinical action to plans for a future interrupted by lack of knowledge of adverse genetics, this chapter has demonstrated the complex range of actors and narratives relating to prognostics.

From documents written specifically for the newly diagnosed, and clinical research papers, through specialist-led information on dedicated sites and blogs aimed at CLL patients and patient's own narratives, the chapter has traced how various approaches to CLL prognosis translate across varying professional and personal contexts in CLL networks. Key actors emerge, some such as Chaya Venkat of CLL Topics, and the late Terry Hamblin of Mutations of Mortality, directly mediate information as authors and science/medical professionals setting up nodes in their own right. Others, such as Professor Pettit, are co-opted into the networks to form the role of translating professional information for newly diagnosed patients on dedicated support sites. Clinical papers such as that written by John Gribben on CLL treatment are sourced from medical journals and linked to advocacy sites such as Lymphomation, giving patients in the network a clinical perspective on their disease. More generic sites such as CancerGuide.org act as repositories for contextual narratives such as Stephen Gould's 'The Median isn't the Message' which was linked from popular Listserv ACOR and referred to by several respondents to the survey. Finally, several of these narratives and further links can be found in the narrative

exchanges of patients in a CLL support Community, showing how a variety of narrative perspectives on or 'objects' of CLL are mediated, transported and translated across the particular networks mapped in this chapter.

The IOB survey showed 39% of respondents claimed to actively post research they had come across themselves in order to help others, and there was strong evidence of this type of network activity related to CLL prognosis. This was perhaps unsurprising given the rapidly evolving and complex nature of prognostic research, and peoples' desire to understand it in order to relate it to their own and fellow actors' situations.

Some key themes have emerged. At a human level prognosis is clearly an issue fraught with complications for patients and their physicians as the tensions between prediction, prognosis, time and identity play out in the lives of those who must live with the disease. Whatever prognostic numbers and graphs might come our way as patients, they all translate to a temporal endpoint – 'when will my disease progress?', 'when will I die?' Even at a point where prediction as a basis for treatment choices competes with abstract prognostication, it is still ultimately about managing the disease so we can live longer. "Living in prognosis, then, is about living in the folds of various representations of time" (Lochlann-Jain, 2010: 80).

It is very clear from some of the examples used to demonstrate the chapter that patients are networking online, often in collaboration with professionals, in ways that contribute significantly to their understanding and informed consideration of their own prognostic factors.

As the chapter shows, this doesn't necessarily translate to a desire to know everything for all patients and definitions of empowerment need to take into consideration the fact that a patient may in fact feel empowered by *refusing* to face a prognostic future they have little power to control in the current treatment landscape. As biological knowledge of CLL evolves rapidly however, so do the means to treat it and purely prognostic biomarkers are joined by more predictive markers that may in fact have an impact on evolving treatment options. In such a future, patients may indeed have more choices to make about future treatments and that raises an important question for those who currently prefer not to know, or locate themselves as passive recipients of the knowledge handed down to them by their medical team as the following survey respondent does in admitting that:

*I do not know if I have ever had prognostic testing if so never been told* (IOB Survey Respondent 126).

Importantly, this chapter also demonstrates what it means for patients to be located at a point in history where new knowledge and resources supersede traditional ones at differing rates across the networks. Some patients in the US for example are already well established in trials of novel agents, now gradually spreading into Europe, yet many of the (particularly treatment naïve) UK patients observed in this work at the time of writing remain outside the parameters of access to the new drugs. Exposure to exciting new developments in prognostication and treatment through online debate and discussion, whilst caught up in the regulatory lag of pharmaceutical trial bureaucracy, and the financial implications for healthcare governance of

expensive novel agents places many patients in an extremely frustrating position.

One survey respondent talked of the difficulties of negotiating the current prognosis landscape, stating that *'I have come to expect that the whole issue will be moot in the very near future. The new targeted nonchemo therapies will mean everyone can expect a good prognosis'* (IOB Survey Respondent 86). These gaps between the global perspectives of disease management that networked omniscience offers patients, and the often very different realities encountered at local points of delivery run throughout my findings, and raises questions about how network activity might be actively harnessed towards universalizing care approaches, and towards managing patient expectations where there this is not an appropriate or achievable response. This is a key point arising from the research, and will be returned to in conclusion.

Whilst it would certainly seem that future CLL patients might reasonably expect at least a better prognosis, trials are still at an early stage and results across the heterogeneous spectrum of CLL presentation remain to be seen. However, the sense that the potential for a trouble-free future for CLL patients sits on a tantalizingly close horizon whilst many of us still struggle with the significant issues of prognosis and treatment in the current landscape was tangible across the networks. This raises interesting questions about what happens when a patient group becomes educated at a faster rate than new developments can be translated into access to clinical management and treatments within the existing systems of health care delivery that serve them.

Respondents viewed prognostic indicators variously as necessary tools for controlling the impact of CLL on their lives, useful in the short term but too unstable to be of long term relevance, or unnecessary and even frankly unhelpful. A sense of loss of control of one's life is a major feature of living with disease. As one cancer patient puts it "My choices were never final... My physical state was never constant" (Goldstein, 2000, pp.95-96, cited in Vance, 2012). These 'event limits' (Vance, 2012), and restrictions on individual autonomy imposed by unpredictable progressive disease are frequently articulated by CLL patients, for whom prognostic knowledge becomes a means of seizing back at least some degree of perceived control. For some survey respondents this equates to having ballpark survival figures around which they can make life plans accordingly. Interestingly, several respondents actively sought this knowledge despite openly acknowledging the frankly unreliable nature of prognostic indicators, their tendency to change, and the fact that overall outcomes don't always correlate with prognostic indicators.

Even those intentionally electing *not* to engage with prognostic resources are exercising a form of control over the potential for results to invoke anxiety and helplessness, choosing instead to "live in the moment". For all of us with CLL then, prognosis remains a vexed issue. As with CLL treatment itself, prognosis is also a dynamic field, with new indicators and tests being discovered on an ongoing basis, giving CLL experts cause to reflect on how they may be validated and incorporated into new treatment approaches and strategies for their patients. For example, Minimal Residual Disease (MRD) testing can now identify micro levels of disease in the blood and bone marrow, with the potential for assessing the efficacy of treatment, and



as early warning of returning disease following treatment through regular monitoring. Trials to assess the effectiveness of obinutuzumab monoclonal antibody consolidation therapy for those with remaining or rising MRD following treatment are currently in set-up in the UK<sup>75</sup>.

Interesting work is also being undertaken in the area of mutations in the Notch signalling pathways, with particular reference to mutations in the Notch1 gene in CLL<sup>76</sup>.

For those patients with progressive disease, prognosis is inextricably linked with treatment, and the next chapter will pick up on these themes in a close reading of the exchange of treatment narratives in the networks.

<sup>75</sup> At the time of writing, the Galactic Trial (GALACTIC: GA-101 (obinutuzumab) monoclonal Antibody as Consolidation Therapy In CLL) is in set up as a phase II/III, multi-centre, randomised, controlled, open, parallel group trial across the UK. Its purpose is defined as : To test whether consolidation with obinutuzumab to eradicate minimal residual disease (MRD) in B-CLL patients who have recently responded to chemotherapy leads to prolonged progression-free survival (CTRU, Leeds, 2015)

<sup>76</sup> Willander et al. contend that NOTCH1 mutations are a novel risk marker on the basis that “Both NOTCH1 and TP53 mutations seem to be independent predictive markers for worse outcome in CLL-patients” (Willander et al., 2013).

## Chapter 5: Treatment

### Introduction

*The kinase inhibitors, in particular, which I would know nothing about were it not for the various lists I belong to, have made me feel--perhaps naively--rather "safer" than I used to. I no longer have the sense that I have a sword of Damocles hanging over my head, or, if it is, it is hanging by a sturdy rope, not a thread (IOB Survey Respondent 25).*

*...It gives all of us hope that at least we are closer and have a chance, rather than being burdened with this 'incurable cancer' label which in itself can seem hopeless... (IOB Survey Respondent 18).*

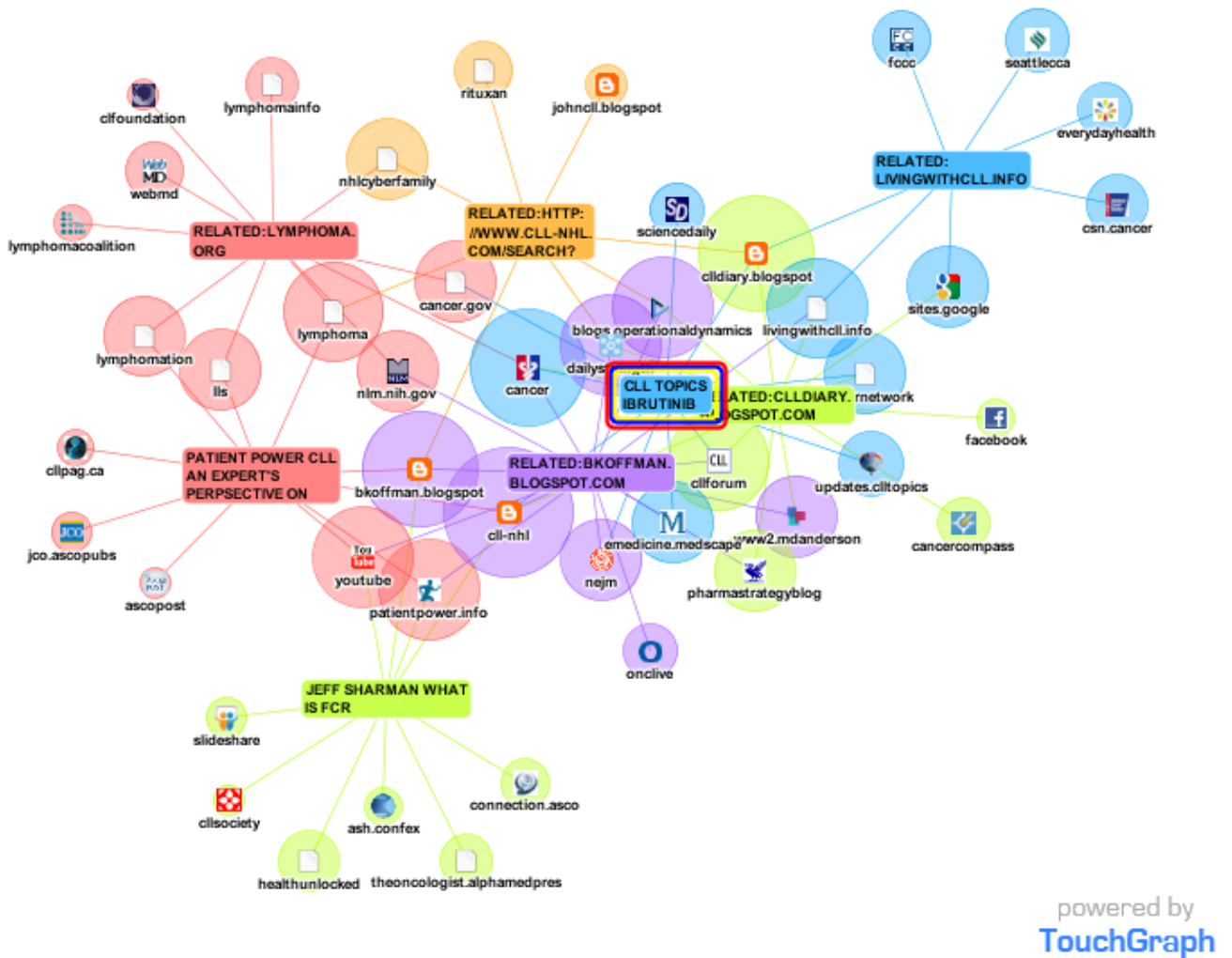


Figure 26: TOUCHGRAPH (2015) network connections between sites used for Translations in Treatment chapter [Network Map]. [Online] Available at: [www.touchgraph.com](http://www.touchgraph.com) [Accessed 17/05/2015].

The Diagnosis chapter outlined the Scylla and Charybdis of watch and wait versus treatment for those travelling inexorably through the lowlands of fatigue, and frequent infection as their tumour burden increases. Unlike many acute and more aggressive cancers however, CLL does at least generally bring with it the relative 'luxury' of time to consider treatment options. As the

Prognosis chapter has shown, the heterogeneous cytogenetic presentation of CLL calls for a range of treatment approaches. Traditional 'gold standards' of care are based on a range of CIT options, the most common (for patients without a 17p deletion) being a combination of Fludarabine, Cyclophosphamide and Rituximab (FCR). Advancing genomic knowledge is changing the world of cancer treatment however and CLL, once regarded with little interest as a disease predominately of old men, now plays an active role at the forefront of cancer research. CLL was singled out for ASCO's cancer treatment advances of the year 2014/15, and online CLL communities buzz with anticipation about new treatments. We are moving it seems towards a time when long-term palliation with toxic agents, will be replaced by long-term management with gentler regimes, and the potential of a future "cure" for the disease occasionally whispers across the networks.

I was interested in how this environment of hope and massive optimism might impact on CLL patients in the here and now, and how and where they got their information from about these new treatments. The IOB survey attracted 157 text responses to this question, with respondents generally articulating optimism about the potential of new, less toxic treatment regimes, and citing CLL networks online as a dominant source of information:

*Fill me with so much hope and at the end of the day touchwood I will be ok that's all you want through all this is someone to say you will be ok but you can't at the moment. I'm tough as old boots now (IOB Survey Respondent 207).*

*I keep up with what's happening mainly through ACOR and Patient Power (Andrew Schorr). As for my attitude, all this progress is beginning to make me a bit concerned*

*that I might actually get "cured" and find myself 94 years old, blind and toothless (IOB Survey Respondent 90).*

*Mostly I read the forums for the links others post on research and news. I read hundreds of abstracts from the ASH [American Society of Haematology] Conference. What seems to be happening with treatment and research make me wonder what I was so concerned about just last year (IOB Survey Respondent 86).*

*I have a much better attitude after learning about promising new treatments, and no longer look at SLL as my husband's "death sentence". Nor do I look at future chemo as a foregone conclusion. He might be able to take an oral agent with better success rate and fewer side effects. I would not know any of this without the internet (IOB Survey Respondent 84).*

Despite this optimism, the idea of a "cure" produced widespread scepticism across the responses, patients aspiring instead to manageable disease and less toxic treatments:

*I'm glad to see the mortality graph lines flattening a bit, but I take the talk of "cures" with a keg of salt. I am aware that often the lab touting a cure is also hoping to profit from the sales of it (IOB Survey Respondent 110).*

*...Cure? have you any idea of the genetic changes in the CLL cells? Unlikely isn't it. Lets [sic] settle for good remissions (IOB Survey Respondent 169).*

Unsurprisingly, there was a clear distinction in responses between treatment naïve respondents still in watch and wait for whom the likelihood of access to new drugs when needing treatment is greater, and those fast approaching, currently in, or previously having been treated:

*ok, here I get quite lost. I have read about some of them but until i get to a stage where I need treatment I am just sitting back and ignoring it mostly - will it be available? will the NHS pay for new treatments? when will I need it? don't know.... so not worrying too much about it at this stage - what will be will be, and I just hope its the best that can be accessed at that time (I do wonder that my local Consultant(s) are fully versed in all aspects of CLL, i don't have much faith in them, which worries me). I use CLL Health Unlocked to keep an eye on comments about new treatments - interesting but not relevant to me at this stage - this is only because the alerts pop up daily and I see the references in the titles within the notification emails, otherwise I would not be researching this aspect from other sites (IOB Survey Respondent 187).*

This respondent shows how the site architecture of CLL Health Unlocked as read through the notification e-mails they receive daily, alerts them to and keeps them in touch with topics they may not otherwise follow. When the time comes for treatment, this respondent will be well versed in the changes that have taken place in protocols simply through daily contact with the community.

Equally though, those having experienced the unpleasant or toxic effects of chemo already and, in some cases, running out of options with them, were optimistic at the prospect of future non-chemo therapies:

*I am hoping I dont [sic] have to have FCR again, something easier on the body, I know I will need further treatment as I have a more aggressive type, the internet allows me to read research, sadly this is mostly from the USA (IOB Survey Respondent 210).*

The cumulative effects of previous treatment, or adverse treatment reactions can leave patients feeling that they have burned some of their future treatment bridges, and for some of

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these patients the future is viewed with a degree of trepidation, despite the generalized excitement:

*I would be more excited if I had not reacted badly twice to BR with the result I am now on FC without R, where remission is not statistically very long. (IOB Survey Respondent 224)*

For some CLL patients, particularly those in the US, or fortunate enough to throw lucky dice in randomized trials here in the UK and across Europe, the hype presages reality as they enter into a treatment landscape in which highly toxic chemotherapy is no longer the only option for staying alive. The internet was cited as a major source of information for trials giving access to the new drugs:

*Again I am in a cutting edge trial because of the internet (IOB Survey Respondent 32).*

So the current binary tradition of watching until waiting for treatment that, in itself, is a risky prospect, may soon be superseded by the potential of new prognostic and pharmacological technologies to create more nuanced, individually tailored, and safer treatment protocols. For all of us living with CLL now this is undoubtedly good news. It brings with it though inevitable frustration for those needing treatment at the cusp between traditional approaches to care and emergent brave new protocols and concern about time scales and access to the novel agents was commonly expressed:

*Since I know that new treatments and drugs take a long time to find their way into the market place, and since I don't know when I will need treatment, I don't hang a lot of hope on them being available to me. I completely trust my doctor to know about availability of new option and trial studies (big city, specialized leading hospital, doctor being a CLL specialist, etc.)..... I use the CLL topics, CLL Canada, and other credible online resources to read about new developments (IOB Survey Respondent 107).*

Observations were also common surrounding the current lack of reliable evidence surrounding side effects and long term survival rates with the new drugs:

*UK CLL Forum- medics site. You might be able to access some of these treatments as a trial, but there is no firm evidence of common cures or good remissions for secondary or tertiary treatments... (IOB Survey Respondent 169).*

In relation to access, serious questions are raised about the current process for getting drugs from research to market, the clinical trials process, drug pricing and the relationship of the pharmaceutical industry with global health care systems. The road from research to market for drugs is a slow one, trials are not always available in a patient's health care region, clinicians aren't always prepared to prescribe drugs recently licensed for use with specific patient groups "off-label" to other patients who may benefit from them and health authorities may not approve prescription of new drugs with a high tariff. In reality then, patients currently facing treatment can find themselves with little or no choice at all but to accept traditional (cheaper) chemoimmunotherapy, despite the prevailing discourse of hope and change, or hope for



compassionate access<sup>77</sup>:

*....most promising time for newly diagnos, [sic] around the block a few times hoping compassion use will be available now.... (IOB Survey Respondent 49).*

Obstacles to accessing novel agents constitute a number of factors from the economic to the regulatory. In addition, this work has demonstrated the significant role that access to information about new treatments and trials plays in accessing the treatments themselves.

Patients not hooked into CLL information networks are vulnerable to this weak link in knowledge exchange, especially if their doctors are non-specialists, and/or their treatment centres don't participate in trials. However, it is clear that, even for some networked patients, difficulty in assimilating and making sense of often highly scientific reports and debates surrounding new treatments in relation to such a heterogeneous disease with differing treatment protocols can leave them feeling equally confused and ill informed:

*I only look at the CLL newsletter when it is sent to me. I am not scientifically minded and I find a lot of the information online is not really written for patients but for professionals who understand it (IOB Survey Respondent 199).*

*Currently I am totally bamboozled. I need to find time to zone in on issues key to my situation, and at the moment I think this might be challenging - there is a lot of buzz*

<sup>77</sup> Some drug companies themselves will initiate what are often known as compassionate or 'named person' access to their new drugs still in trials, or negotiate confidential discounts with payers for innovative drugs considered too risky or costly on what are known as expanded access programmes for patients for whom new drugs represent a significant benefit over what is already available. These access routes still require approval by the appropriate regulatory body, and by the prescribing clinician, and are wholly at the discretion of the drug companies in question. See EMA European Medicines Agency (EMA) 2007.

*(which is good), but how do you focus on the specifics to the individual situation?  
Making this simpler would be good! (IOB Survey Respondent 131)*

Problems with medical literacy can be seen to have the consequence of undermining effective self-advocacy among patients. Engagement with a range of circulating narratives is only as empowering as a patient's capacity to understand them, or to have them translated on their behalf. The previous chapter has outlined some of the network activities undertaken contribute to these processes of 'translation' or explanation, and going offline to consolidating often complex online information in face to face settings can be an effective strategy for enhancing understanding:

*It was very very very interesting to hear the talk by Prof Pettitt at a recent NW CLLSA meeting. The talk explained a lot more than I'd been able to previously understand by reading online resources (IOB Survey Respondent 148).*

As with other areas of this research, not all patients surveyed extolled the virtues of pro-active patienthood through online networked activity. Although in the minority, some respondents profess to reliance on their doctors to keep up for them:

*I rely on my consultant to give me the appropriate treatment (and to look online himself!) (IOB Survey Respondent 216).*

Others confessed to not keeping up with developments at all, although two of those mentioned that the survey itself had inspired them to be more pro-active in the future, demonstrating its

own network effects:

*CLL is in the back of my mind most of the time, I didn't even know about these new treatments and trials in the pipeline (IOB Survey Respondent 219).*

*I'm afraid I don't keep very up to date with them - but maybe I will now...(IOB Survey Respondent 246).*

*It is good to know that such advances offering hope of better things to come are being made but I somehow feel separated from them and have as yet not looked into any of it online. (perhaps now I will as this survey is renewing my desire to discover more) (IOB Survey Respondent 160).*

Motivations for engaging with online information or otherwise differ however, and the following respondent eschews online discourses of cure and longer remissions in favour of a more spiritual approach to living and dying well with CLL:

*ASH and the listservs indicated earlier. They don't really change anything. Whether I die in 2 years or 20 years doesn't matter. Embracing mortality, using the life I have and preparing for a graceful, loving and hopefully even humorous exit is what matters to me (IOB Survey Respondent 70).*

Network sites mentioned in the IOB responses include blogs by physicians, Jeff Sharman, and Brian Koffman, Andrew Schorr's Patient Power site, Chaya Venkat's CLL Topics, CLLSA UK HU, and several references to ASH (American Society of Haematologists). Fieldwork shows that a significant amount of network traffic is concerned with issues surrounding CLL treatment, from

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raising bigger political and institutional issues of access through informed debate, and organized large-scale advocacy to everyday exchanges of the experiences of side effects and how to manage them.

Building on these responses, this chapter explores circulating narratives in a network living through an evolution in approaches to the management and treatment of CLL. This is a network in which the traditional and the new come together through complex explorations of biomedical science, in which discourses of hype and hope for novel treatments and personalized care targeted at individual genetic profiles play out alongside the pragmatic realities of access, the political economy of the pharma industry, its relationship with health care governance, and the legal and regulatory systems that frame the drugs market.

In line with mapping out this territory, this chapter will focus on four main themes in the circulating narratives of treatment: 1) new approaches to treatment and management of CLL, and their impact on the networked patient population; 2) narratives of cancer treatments in the mainstream news media and network responses to these; 3) the role and inscriptions of the pharmaceutical and biotech industries in the networks; and 4) access to CLL treatments (including trials), and the variety of approaches to networked information exchange surrounding treatment and its effects including organized advocacy and big data.

The circulating narratives selected for the Translations sections align with these interests and include an entry entitled 'What is FCR' from US Haematologist Dr. Sharman's blog, a page from

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CLL topics exploring access to novel agents, a news feature on novel agent ibrutinib, postings to support sites sharing information about clinical trials and drug side-effects, and a snapshot of the CLL group on health data sharing site PatientsLikeMe.

## **Perspective: The changing landscapes of CLL treatment (Living with CLL on the Cusp)**

CLL received its first mention in the medical literature in 1827 (in relation to a 63 year old Parisian florist turned lemonade vendor, Monsieur Vernis), and was distinguished as a distinct form of leukaemia in the mid nineteenth century. Little else changed up until the nineteen fifties when the nature of the immune deficiency underlying the disease was defined, and a handful of drugs able to temporarily slow down progress (chlorambucil, melphalan, mechlorethamine and corticosteroids) emerged alongside radiation therapy to enhance palliation.

As the prognosis chapter has shown, the staging systems introduced by Rai and Binet in the 1970s went some way to predicting survival for cohort, but did little to predict individual progress of this heterogeneous cancer. Early intervention for those in high-risk cohorts was largely unsuccessful, often exacerbating decline. The emergence of cytogenetics and IGH mutational state discussed in the Prognosis chapter led to the ability to identify those with a particularly poor prognosis. At the same time, the advent of fludarabine and cyclophosphamide, followed by rituximab and eventually bendamustine and alemtuzumab alongside auto- and

allotransplants<sup>78</sup> made some impact on the outcomes of high-risk CLL but the disease remains incurable. Improved understanding of the molecular antecedents and biology of the disease alongside the advent of a new breed of effective drugs including ibrutinib, ofatumumab, obinutuzumab, and idelalisib in addition to Bcl2 inhibitors such as ABT199 make for a more optimistic outlook. Contributing to this optimism is the ability to keep track of the disease at micro-levels through measurable residual disease (MRD) tests with the potential to predict early progress in remission. As Gale and Hochhaus<sup>79</sup> (2015) point out, it remains to be seen whether all or any of this will contribute to a cure.

The initial draft of this chapter was written as I recovered from a six month course of chemoimmunotherapy (CIT) known as FCR. Purine analogs fludarabine and cyclophosphamide make up the 'chemo' part alongside monoclonal antibody rituximab which constitutes the 'immuno' element of therapy. For around a decade since its inception, FCR has been regarded as the gold standard of care for younger fitter patients, and indeed for some of those patients with particularly favourable biomarkers and who remain in remission some 12 years since their

<sup>78</sup> Allogeneic and autologous stem cell transplantation (SCT) are sometimes considered as experimental therapies for high risk younger CLL patients running out of traditional treatment options. Successful SCTs are considered to be the only possible route to 'cure' for some CLL patients, although it is a high risk intervention where even those patients who survive the transplant may still relapse in due course. For a detailed 2002 analysis of the two approaches, See Dreger and Montserrat's (2002) paper, 'Autologous and allogeneic stem cell transplantation for chronic lymphocytic leukemia', published in *Nature* in June 2002.

For a more up to date lay explanation, see also see Sharman (2013b) 'Stem Cell Transplant'. 28.09.13 in Dr. Sharman's CLL & Lymphoma Blog: Translating basic science and clinical breakthroughs into language we all can understand.

<sup>79</sup> Gale and Hochhaus's introduction to the special 'Leukaemia' edition of *Nature* magazine presented with the support of Janssen Pharmaceuticals in 2015 outlines a detailed history of the emergence and evolution of CLL as a specific haematological malignancy in its own right. I am indebted to their work for underpinning the short potted history presented here.

involvement in the first trials, the possibility that it might even provide a 'cure' is being tentatively discussed. However, many patients will in fact relapse within two to six years following treatment with FCR, and around 10% go on to develop treatment-induced further malignancies, often superseding CLL with a potentially more deadly prognosis. As CLL specialist Jeff Sharman notes, "FCR is pretty close to the maximum amount of chemotherapy you can put into a single regimen" (Sharman, 2012).

As the Prognosis chapter has also shown, individuals can now be tested for the particular genetic mutations that characterize their personal disease. The same advances in genetic knowledge have paved the way for the development of novel agents targeted at specific cells. Biomedical advances in the field of chimeric antigen receptors (CARs)<sup>80</sup>, BCL2 inhibitors such as ABT199<sup>81</sup>, and BTK inhibitors<sup>82</sup> such as ibrutinib have produced promising treatments trickling through clinical trials and, in some cases, out into the global marketplace. Figure 26 shows one

<sup>80</sup> CARs (chimeric antigen receptors) are genetically attached to the surface of T-cells, which are circulating immune cells that protect the body from infection. CARs are engineered to persuade the T-cells to seek out certain proteins. All cells have proteins specific to the cell type. B-cells, including CLL cells, express a number of proteins on their surface such as CD19, CD20 and CD23. CLL is a type of B-cell malignancy. The first CARs being used to target B-cell malignancies have been programmed against the surface protein CD19. These CD19-specific CARs have been investigated extensively over the last few years...a CAR study led by Drs. Carl June and Bruce Levine has proven successful with dramatic initial responses in three CLL patients. See Introduction to *CLL Global News – 'CARs Research Speeds Ahead'* - (November, 2011) for further discussion and updates of research in this area.

<sup>81</sup> CLL cells demonstrate overexpression of the B-cell lymphoma-2 protein, one of the standard regulators of apoptosis. The oral drug ABT-199/GDC-0199, in joint development by AbbVie and Genentech, mimics the BH3-binding element universal to all cells, thereby restoring the physiologic regulatory process normally causing cancer cells to self-destruct. See Nancy Melville's (2014) article for *Medscape Medical News*, 'Move Over Ibrutinib? New Agent Shows Strong Results for CLL', for a full account

<sup>82</sup> On the 'Our Science' page of their website, Pharmacyclics describe BTK is an important cell signalling enzyme that is found in hematopoietic (blood) cells including B-cells. B-cell activation is driven by the B-cell receptor (BCR), and BTK is a crucial part of the BCR signalling pathway. BCR signalling is thought to promote cell proliferation, adhesion, and survival in many types of B-cell malignancies (cancers). Inhibitors of BTK such as the Pharmacyclics compound, ibrutinib (PCI-32765), act downstream of the BCR and block BTK activity, and in preclinical models this resulted in an inhibition of proliferation, a disruption of tumor cell adhesion, and apoptosis (cell death) in malignant B-cells.

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of the ways in which this highly scientific information can be disseminated in the CLL support networks, in this case translated for CLL patients and carers in a feature in the newsletter for global CLL charity CLL Global.

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**Figure 27: CLL GLOBAL (2011) 'BTK Inhibitors' in CLL Global Newsletter, 2, 2011 [Screenshot]. [Online] Available at: <http://www.cllglobal.org/CLLnews/btk-latest-news-combined.pdf> [Accessed 03.05.2013].**

Instead of killing cancer cells (and non-cancer cells along with them), small molecule drugs (kinase inhibitors) such as ibrutinib work to disrupt the communication pathways that enable mutant cells to suppress natural cell death or *apoptosis* (and accelerate disease progression), and have been used with great success in the form of gleevec to treat chronic myeloid



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leukaemia (CML)<sup>83</sup>. CLL has a more complex biology than CML though and, despite a raft of novel agents currently going through the trials process and producing promising results with varying patient groups and CLL sub-types, the heterogeneity of CLL doesn't lend itself quite as easily to a one size fits all gleevec equivalent.

Some patients are already in trials or receiving novel agents as second line therapies for which they have won recent approval:

*have just completed a clinical trial of GA-101 monoclonal antibody, with minimal side effects and "a complete response." I feel better than I have in years. Clearly, we are finally making progress in the treatment of cancer, the first real progress in my lifetime, where the treatment isn't worse than the disease. I would not have known about the exciting new options without CLL Topics and ACOR (IOB Survey Respondent 55).*

*I have been through all the protocols. I am now taking an experimental drug that is a kinase inhibitor. It has saved my life. I believe it will be the next wave of treatment – non-toxic & it works! (IOB Survey Respondent 29)*

As already demonstrated though, evolution to a world without CIT is a slow process with no guarantees, leaving many CLL patients currently facing treatment with traditional CIT with all of

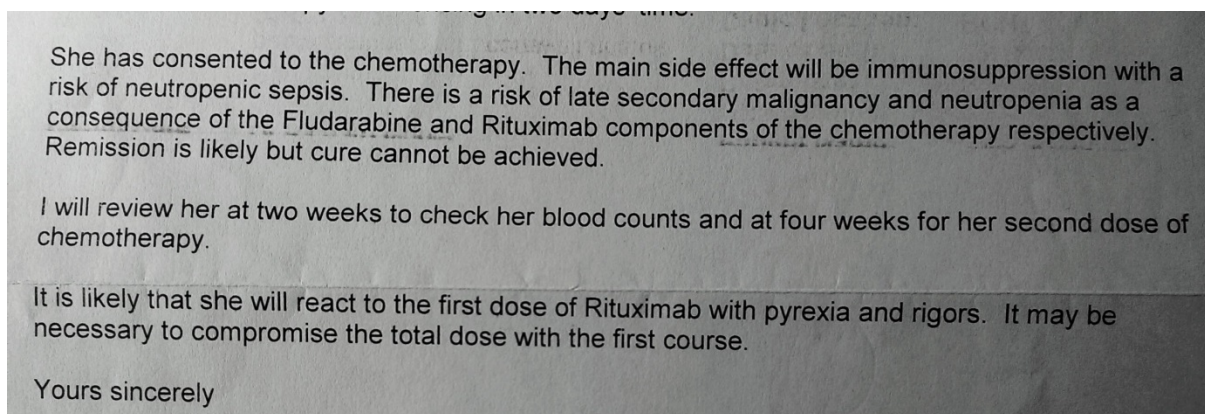
<sup>83</sup> Investigations of the BCR-ABL tyrosine kinase as a target for therapeutic intervention led to the discovery in 1993 by Brian Druker of STI571, a compound capable of killing CML cells in vitro while preserving healthy cells. In 1998, STI571 underwent its first human clinical trial. Now commonly known as Imatinib Mesylate or Gleevec, the drug is at the forefront of the quest to develop personalized therapies for haematological cancers and has redefined CML, once a life-threatening cancer, into a manageable chronic disease, raising hopes that similar agents could be developed across the spectrum of blood cancers (see the National Cancer Institute paper: 'YS Budget 2003' for further information).

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its toxic implications:

*I wonder whether these new treatments will be available 'in time' for some of us. I'm encouraged by them and I am sure there will be a 'cure' in time and happy for those who will be able to take advantage of them. Meanwhile, we will have to take the 'toxic shock' of chemo... Patient Power and CLL Support Org in Health Unlocked are resources I have used to keep up with developments (IOB Survey Respondent 180).*

Although revolutionary changes in treatment open doors onto a possibility for relatively low-impact long-term management, as it stands many CLL patients must acknowledge that sooner or later their bodies and available treatment options may well run out of resources to fight the disease. As my own consultant's letter to my GP informing him of my treatment starkly states, 'Julia has commenced FCR treatment...remission is likely, but cure cannot be achieved.' (See figure 27 below for an excerpt from that letter).

A scan of a handwritten letter on lined paper. The text is written in black ink. The letter discusses chemotherapy treatment for a patient named Julia, mentioning side effects like immunosuppression and neutropenic sepsis, and the use of Fludarabine and Rituximab. It also mentions a follow-up appointment at two weeks and a note about a potential reaction to the first dose of Rituximab. The letter ends with 'Yours sincerely'.

**Figure 28: RCHT (2013) Extract from Consultant letter to my GP [Scan].**

As with other forms of cancer, contemporary CLL patients and their clinicians must negotiate a complex landscape of individual cytogenetics, existing chemo-immunotherapeutic treatments, emerging novel therapies, and the issues of regulation, access and affordability that accompany them. Networks are currently populated by narratives and actors located at various points on the current treatment continuum. Inevitably, many CLL patients will find themselves excluded from access to new treatments, and must find ways of negotiating any potential frustrations within their own narratives:

*I have accepted what I have and I believe that the consultants are giving me the best treatment possible at the present time. I am glad that progress is being made with new treatments, but I am not going to feel that I have been cheated because the new treatment is not available now. I need to live now with what I have and what treatments are available now. Any jealousy, if that is the correct word, for any future sufferers who receive the new drugs/cure will not help me, and there is very little made of how lucky present day sufferers are compared to CLL sufferers in the past. We are lucky compared to them and hopefully every future generation will be luckier than the present/last one as progress is made to cure CLL... (IOB Survey Respondent 179).*

As this response implies, whether or not they receive new treatments, the contemporary CLL patient is undoubtedly in a better place than their historical counterparts, and there will always be transitional phases in which some patients are benefitting from new treatment advances whilst others are not. My own story of beginning treatment is not an unusual one and, coming when it did right on this cusp of treatment paradigms, serves to represent some of the dilemmas and frustrations faced by those of us directly straddling the old and new worlds. Diagnosed in March, 2011, the status of my CLL as progressive was clear, although relatively contained for the first two years. My wbc was 67k on diagnosis, and hovered just below 200k

some two years later. A lymphocyte doubling time of six months or less is considered indicative of a need to treat and mine, although rising inexorably, had not demonstrated such a leap. By summer 2013 however, it became clear that my disease was 'taking off' as my lymph nodes became more swollen, and my spleen palpable, a fact confirmed by my consultant at my regular check-up in September. Although I knew I had a progressive CLL, the rapidity with which it became aggressive and requiring urgent treatment was unexpected, and I began trawling online for information on treatment where it became clear that new treatments were causing much excitement and hope, but that not everyone needing immediate treatment would be part of that.

The following three Translations focus on ways in which these sometimes disparate narratives of hype, hope and reality are playing out among patients in CLL support communities, and evidence complex narrative associations and translations from physician blogs, through patient advocate sites, to personal opinion in online support communities.

## Translations: Hype, Hope and Reality: Staying alive in the interstices of the treatment revolution

### Translation 1: Dr Sharman's CLL and Lymphoma Blog: 'What is FCR?'

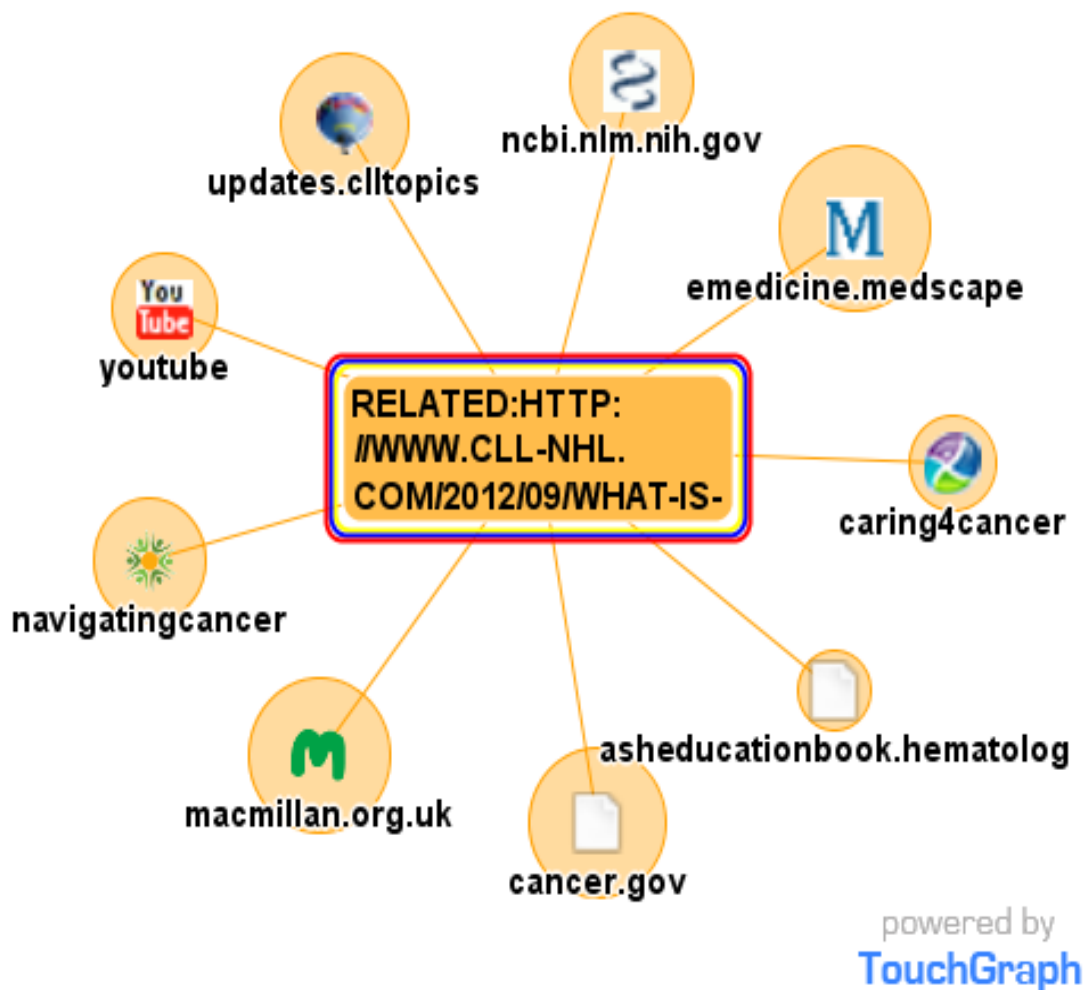


Figure 29: TOUCHGRAPH (2012) Network connections to Dr Sharman's CLL and Lymphoma Blog post 'What is FCR?' [Network Map]. [Online] Available at: <http://www.touchgraph.com/seo/launch?q=http%3A%2F%2Fwww.cll-nhl.com%2Fsearch%3Fq%3Dwhat%2Bis%2Bfcr%23.VTO6gvnF-So%20%20%20%20%20%20%20> [Accessed30/11/2014] .

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During this period I encountered many network narratives extolling the virtues of new treatments and looking forward to a chemo-free future, and I also encountered a useful entry on a blog by physician Jeff Sharman. I will start with a brief outline of that blog as a network narrative that sets the scene for the dilemmas faced by patients and physicians alike in navigating the changing terrain. Entitled 'Dr. Sharman's CLL and Lymphoma Blog: Translating basic science and clinical breakthroughs into language we all can understand' (see figure 29) , haematologist-oncologist Jeff Sharman's blog is a highly popular node in the networks, mentioned frequently in the IOB Survey, and experiencing a significant flow of traffic.

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**Figure 30: SHARMAN, J. (2012) 'What is FCR?' [Screenshot]. Dr. Sharman's CLL & Lymphoma Blog. [Online] Available at: post [http://www.cll-nhl.com/search?q=what+is+fcr#.VTkyl\\_nF-So](http://www.cll-nhl.com/search?q=what+is+fcr#.VTkyl_nF-So) [Accessed: 24/04/13].**

A practicing haematologist at the Willamette Valley Cancer Institute in Eugene Oregon, Sharman is also Medical Director of Haematology Research for community based research

network US Oncology, with sites throughout the United States. Acknowledging the impact of time restraints in the clinical setting on the level of discussion and explanation of CLL achievable, he describes his blog as an additional resource for the patients he sees on an everyday basis:

In our visits, I often find I want to give a more comprehensive discussion than what time allows. I hope this blog allows my patients to feel more informed about what we are doing and why we are recommending it (Sharman, 2012a).

Seeking to use online resources to set out the broader research contexts within everyday clinical decisions are made and put into practice for his patients, Sharman is demonstrative of the kind of clinician at the heart of evolving models of clinical knowledge exchange and partnership proposed by Tom Ferguson in his e-patient white paper (Ferguson, 2007). With slightly under half a million visits to this page alone, it is clear that his remit extends way beyond his original intended audience of his own patients. Jeff Sharman is a key actor in CLL networks online, his blog pages reflecting the dominant current debates among patients and clinicians in the field and translating them for lay audiences.

The post explored here is entitled simply 'What is FCR?', and appeared on 14<sup>th</sup> September, 2012<sup>84</sup>. Sharman begins by addressing "a lot of emotional debate among academic physicians" about how broadly to utilize FCR, currently the standard regimen for most CLL patients.

<sup>84</sup> As at 27th October, 2014, total page views for the post registered 431,398.

Drawing on “patterns of care” data from leading global CLL researchers, Sharman makes a distinction between the “real world” of 90% community practice, 10% academic clinicians” (Sharman, 2012a). This is important as non-clinical readers can reflect on the *actual* landscapes within which they are treated. Much like global news networks, the CLL networks tend to amplify the more dramatic and outstanding stories, and to source big stories of treatment advances from a limited range of key voices in the field. On the whole, those key clinical voices circulating in the networks tend to represent Sharman’s claimed 10% of academic clinicians, which are not necessarily representative of the remaining 90% of clinical providers servicing most of the CLL population through smaller regional centres. Small wonder perhaps that the leading stories of change and progress don’t always mirror the experience of many patients in the network (nor presumably those outside of them). The playing field for CLL patients is by no means a level one:

If you have the means, resources, insight, and physical ability to travel to Houston you are not the “typical” patient with CLL seen in the community. Consequently, what can be done well there does not always reflect what can be done elsewhere (ie. the input influences the output) (Sharman, 2012a).

This sense of an ‘elite’ group among CLL patients who are relatively young, wealthy, well-informed, and well enough to travel was mirrored in the following respondent’s tangible sense of exclusion:



*...I am also pretty certain that I will be limited to only treatments "allowed" by Medicare. So perhaps there is more hope for those who have more resources in terms of money or accessibility to research hospitals or medical centers that specialize in blood cancers (IOB Survey Respondent 151).*

Optimism for a chemo-free future is tangible but, as Sharman points out, FCR (for all of its flaws) provides some of the most durable remissions currently achievable in CLL. For readers who may understandably have simply black-boxed FCR as ‘chemo’, Sharman explains the way the three drugs work in the body and interact with each other, and sets out some of their long-term side-effects, including the possibility of ‘clonal evolution’<sup>85</sup>. Thus far the reader is in no doubt that FCR, whilst highly effective for particular patient groups, is no free lunch. They will also be aware that this is a contentious area amongst CLL specialists. Sharman makes that clear when he points out that “There are some very passionate feelings out there among thought leaders about the role of FCR and I need to tread carefully here” (Sharman, 2012a).

Again, the ‘black-boxing’ of chemo is exploded as readers are made aware that this particular regime in its broader contexts is about more than cells, symptoms and side-effects. The allegiances, aspirations (individual and institutional), histories and politics of a particular treatment regime are implicit in Sharman’s acknowledgement of the passions invested in clinical approaches to FCR, and in his need as a fellow CLL spokesperson to “tread carefully” around them. He settles on stating that he thinks it is still felt to be the “treatment of choice” in

<sup>85</sup> Whereby all but a bunch of highly resistant clones (usually associated with P53 abnormalities indicated by a 17p deletion in CLL patients but not necessarily apparent on a patient’s initial cytogenetic panel if only present in small numbers) are killed off by the chemo. The resistant genes can then become the dominant gene, and a patient not 17p deleted on diagnosis can become so on relapse, making them difficult to treat with current CIT regimes.

younger, healthier patients without a 17p deletion on diagnosis. However, the impact of novel agents is beginning to erode what Sharman describes as FCRs current “king of the hill” status, and he predicts that we are not “too far away from providing targeted treatments that may allow some patients to never get traditional chemotherapy” (*ibid*). Again, a brighter treatment future is promised, but most readers engaging with Dr Sharman’s blog will be acutely aware of his reminder that “things never move as fast in science as our patients want. Investigators are hoping to “replace” FCR but we have a ways to go before we are there” (*ibid*).

This is precisely the situation I found myself in in September, 2013. Scanning through the daily postings on the Health Unlocked CLL site, I came across links to a number of optimistic circulating narratives discussing a potential chemo-free treatment future. Among these was a video posted to Andrew Schorr’s Patient Power advocacy site on 7th January, 2013, entitled ‘An Expert’s Perspective on Advancing Treatment Progress for Blood Cancers’ (see screenshot in figure 31 below):

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**Figure 31: PATIENT POWER (2013) An Expert's Perspective on Advancing Treatment Progress for Blood Cancers – Dr. Steven Rosen [Screenshot of Video]. [Online] Available at: <http://www.patientpower.info/video/an-experts-perspective-on-advancing-treatment>**

The film shows edited footage of an interview in which Andrew Schorr questions Steven Rosen about his views on the new treatments emerging, and is just one example of an evolving genre of videos depicting interviews between patient advocates and CLL experts and patients posted across the networks. Commonly, these are filmed at conferences or annual meetings of Haematological Associations such as ASH (American Society of Haematologists) or EHA (European Haematology Association) where global experts in the field gather to present on their most recent research findings. Interviews are conducted in a manner that allows for findings to be summarized and presented by clinician-researchers in a way that makes them

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accessible to patient audiences, and directed towards the kinds of questions patients themselves might ask.

The video is of interest for three main reasons: 1) Picking up on the points made in Jeff Sharman's blog, it prefaces the hoped for the imminence of tailored molecular treatment for all – for a chemo-free treatment landscape; 2) it demonstrates how patient advocacy sites are working with clinicians to translate complex treatment issues into accessible video form for networked patients, and using these as a platform to encourage patient engagement and autonomy in selecting clinicians and treatments. This particular video raises some very pertinent points about the changing nature of the patient/clinician relationship as CLL treatment becomes increasingly about long-term management; 3) it demonstrates how circulating narratives such as this catalyse debate among patients relating them to their own personal narratives in support communities. (See appendix 12 for network map and detailed analysis of some of the points made in discussion).

The experience of watching this video (and others like it) is an overwhelmingly positive one, in which advancing biomedical futures translate into the potential of access to treatments that can save or prolong life for all CLL patients. In which the consequent long-term nature of survivorship underpins informed and equal partnerships with clinicians who are interested in holistic approaches to their patients. In which universal agency for patients in terms of choice and access is never seriously questioned. It is encouraging indeed, and is just one of many such videos contributing to the buzz of hope for brighter CLL futures. From my position as someone

entering a very aggressive disease phase and becoming increasingly aware that my treatment choices would be excluding me from novel therapies, as was the case for a significant number of CLL patients in similar positions posting in the forums, it was at the same time incredibly frustrating, and motivated my response to the posting of the video discussed in the following translation.

## Translation 2: Approaching Treatment with FCR in a Support Community (Patient Experiences)

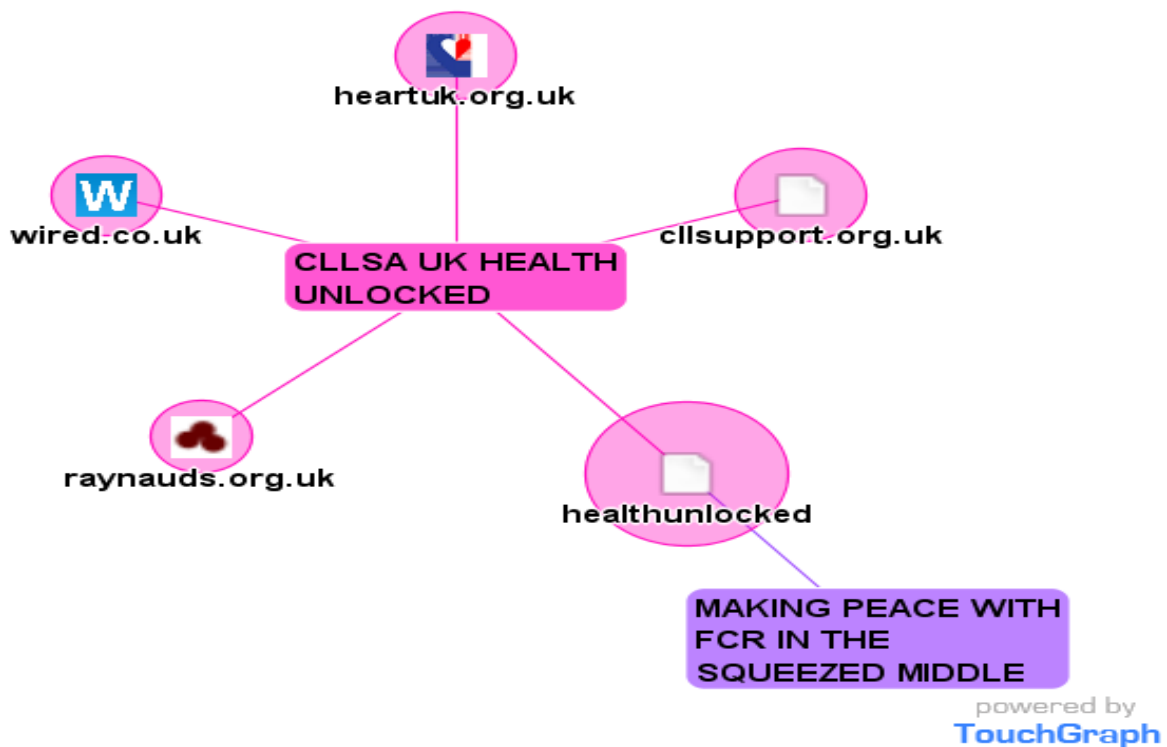


Figure 32: TOUCHGRAPH (2013) Network connections to Jibs60 post 'Making Peace with FCR in the Squeezed Middle on CLLSA UK HU [Network Map]. [Online] Available at: <http://www.touchgraph.com/seo/launch?q=making%20peace%20with%20fcr%20in%20the%20squeezed%20middle%20jibs60> [Accessed: 22/04/15].

Image removed due to copyright restrictions

**Figure 33: JIBS60 (2014) 'Making Peace with FCR in the Squeezed Middle: Response to another very hopeful video from Steven Rosen' [Screenshot of forum discussion on CLLSA UK HU]. [Online] Available at <https://healthunlocked.com/cllsupport/posts/130236845/making-peace-with-fcr-in-the-squeezed-middle-response-to-another-very-hopeful-video-from-steven-rosen> [Accessed 23/04/2015].**

The screenshot replicated in Figure 32 (above) shows my response to the Steven Rosen video posted to the CLLSA HealthUnlocked site in September, 2013. Starting my response by observing that:

it's brilliant to see such optimism, and to hear someone say that he can tell his CLL patients that they'll never need chemo...however, for those of us facing an imminent need for treatment now...those of us in clear and present danger that isn't going away while we wait until early 2014 in the UK to see if we can get a 50/50 chance of ibrutinib in the .... phase 3 trial, I'm afraid it simply isn't true... (jibs60, 2013).

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I went on to point out that, with a rapidly growing spleen, increasingly bulky nodes and anaemia/thrombocytopenia alongside crashing fatigue and frequent infections, my own treatment 'choices' were starkly limited. I could, against medical advice and the insistent warning signs from my own body, wait for a trial to start up somewhere local for a 50/50 chance of getting access to ibrutinib (potentially missing the window of opportunity to start treatment while fit enough to respond well). Alternatively, I could just go with FCR (given that there's a 50% chance that's what I would end up with anyway), and that was the decision I felt I had no choice but to make. I made it clear that, whilst I welcomed the possibility of a durable remission offered by FCR, and didn't wish to undermine the optimism for brave new treatment futures, I found it incredibly frustrating that so much of the optimistic discourse elides the present reality for many of us as if it has just conveniently disappeared:

...this is a tough place to be right now, and to acknowledge that for anyone else in a similar position, and for those who may draw the FCR arm in the upcoming randomized trials. We will all need to find a way of making peace with, and retaining a positive attitude to our experiences with a treatment that is already being consigned by many to a rhetorical past, but that we must rely on to keep us alive in a present already overlapping with a future buzzing with hype and hope for another way... (jibs60, 2013).

Of the 25 responses, all were supportive and expressed empathy for the sense of frustration experienced at the overwhelming failure in the majority of circulating discourses of new treatment to acknowledge the fate of very many CLL patients still consigned to traditional treatments in the interim:

So well put J. I am sorry to read that treatment time is here and recognize how frustrating some of the hype and insensitive messaging contained in these broadcasts must be especially to the younger untreated patient (Hairbear, 2013).

And this community member, also facing imminent treatment with chemotherapy concurs with what she suspects is a widespread sense of frustration:

Your post explains precisely the frustrations that I (and I suspect many others) are struggling with, though we can't always express it as clearly as you. (I too am treatment naive, but have been told to expect treatment within the next year, of either R Bendamustine or FCR) (Anonymised HealthUnlocked community respondent).

This sense of frustration was mirrored by a number of ITB survey respondents:

*It is exciting to know that a lot is happening on the CLL front, but a little caution about immediate availability is in order (IOB Survey Respondent 107).*

Due to a number of perceived mitigating factors around access and efficacy, patients spoke of not wanting to get their hopes up surrounding the prospect of radically improved prognosis or cure. One patient articulated the potential damaging impact in emotional terms for CLL patients of over-zealous optimism from clinicians:

*I'm afraid to get my hopes up. I was at the CLL Conference in Niagara Falls last year (fantastic!) and a Dr. from the states was saying how CLL would be cured in the next couple of years. I think his positive attitude was good but he played with our emotions.*



*For us will CLL it is very serious when you say something like that (IOB Survey Respondent 118).*

In a response that draws attention to the ongoing cycle of evolving cancer treatments, and the history of those patients that must negotiate them, another forum respondent makes analogies with the introduction of rituximab over a decade earlier:

I recall a similar situation 12 years ago when rituxan was in clinical trials. It didn't quite work out as envisaged, but rituxan has become one of the most important cancer therapies ever, and nothing gives a longer remission or overall survival than FCR, other than an allogenic transplant in some cases. I think people loose [sic] sight of this fact, sometimes (Anonymised HealthUnlocked community respondent).

This respondent also makes the point that FCR's status as the therapy most productive of long and successful remissions for particular patient groups is in danger of being overlooked as attention shifts towards the novel agents. Another respondent spoke of his previous successful treatment with FCR which had enabled him to survive long enough to enter a trial for ibrutinib on relapse, again demonstrating that novel agents – albeit as second-line treatments - remain in the bank for those currently needing treatment but unable to access them. Yet another proffered advice to perhaps negotiate with my consultant to try and hold out for the trial using blood transfusions and steroids to avoid the stress of undergoing a therapy that was clearly not my first choice. The latter prompted an interesting response from a fellow community member about the dangers inherent in the tendency shown by some patients to try and stave off CIT for

as long as possible in the hope of access to a safer alternative:

...Both paths (trials and standard treatments) have their uncertainties but doing nothing when the time has clearly come for treatment is an even poorer choice... (Anonymised HealthUnlocked community respondent).

In a subsequent post reflecting on the input of fellow community members who had taken the time to engage with this topic, I summarized my point that facing chemo at any time is not something anyone would take lightly, but to face it at a time where the CLL networks are buzzing with hope for new treatments continually heralded as a huge improvement on the existing regimes with increasing polarity makes it an even more difficult decision:

Richard Furman's recent video on patient power discussed the obvious benefits of ibrutinib in direct opposition to the dangers of FCR in terms of clonal evolution, secondary tumours, and MDS further down the line. Increasingly we see this as a very polarized issue in the available discourse - FCR the devil we know - Ibrutinib the angel (even though we don't actually know it)... and that I think makes it more difficult to feel comfortable about FCR right now (jibs60, HealthUnlocked, 2013).

From 14<sup>th</sup>-16<sup>th</sup> February, 2014, a debate unfolded on the ACOR CLL forum between patients also addressing the difficulties faced by those having to negotiate a treatment terrain growing in its apparent polarity, particularly with reference to the dire warnings often attached to contemporary discussion of FCR therapies in relation to novel agents. The conversation thread was erudite, and highly informed, linking out to four published research papers on the link between clonal evolution and chemotherapy and one on secondary cancers resulting from FCR.

Despite this, several correspondents acknowledged that FCR treatment had enabled them to live productive and useful lives, that they went into it aware of the risks, and that they would do so again. Undoubtedly, this is a debate that is destined to continue through the interregnum period of old to new, and as more information emerges concerning the long-term efficacy of the newer treatments. CLL is certainly not alone as a disease in locating those who live with it in the frustrating interstitial spaces of biomedical advance and everyday access to the drugs that accompany it. Perhaps that frustration might be experienced more acutely in chronic cancers where the sense of having at least some degree of control over treatment issues can appear wholly illusory when progress becomes aggressive and treatment is, as with other cancers, required as a matter of life-saving urgency and limited only to what is locally available.

Certainly, as I became progressively unwell, and the opportunity to be part of the bright new chemo-free future I had hoped to inhabit slipping away from me, I was acutely aware of Jeff Sharman's observations that "things never move as fast in science as our patients want" (Sharman, 2012).



**Figure 34: KENNEDY, B. (2014) 'The fight to avoid chemo is lost' [photograph] private collection Julia Kennedy.**

Never more so than the November afternoon when my fight to avoid CIT with all its attendant side-effects and long term risks came to a definitive end on the chemotherapy ward as I watched the first liquid line of rituximab snake into my vein (see photograph in Figure 33 above).

## Translation: A Network Account of Ibrutinib's Road to Market (Tracing a Complex Journey)

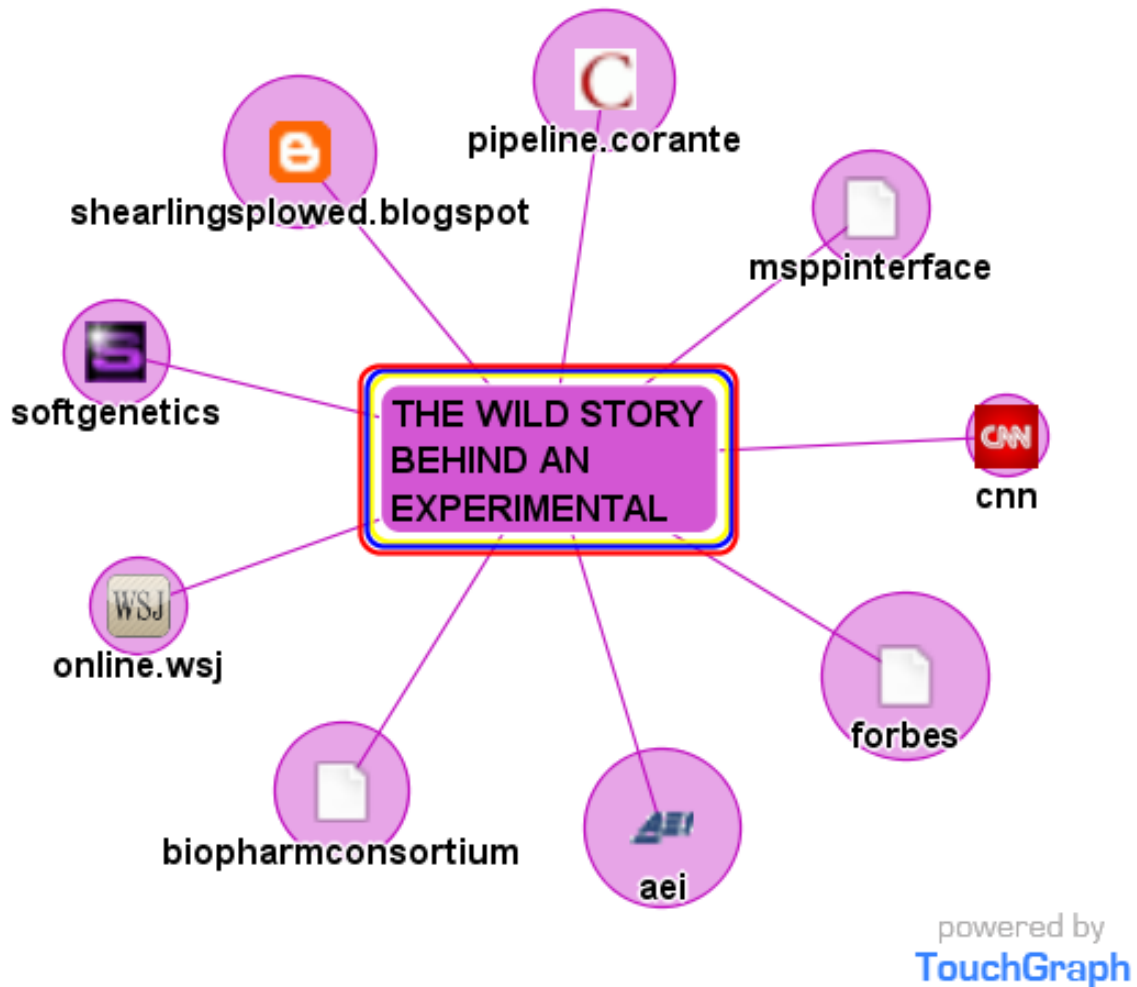


Figure 35: TOUCHGRAPH (2015) Network connections to SHAYWITZ, D. (2013) 'The Wild Story Behind A Promising Experimental Cancer Drug' in Forbes online newspaper [Network Map]. [Online] Available at: <http://www.touchgraph.com/seo/launch?q=http%3A%2F%2Fwww.clinhl.com%2Fsearch%3Fq%3Dwhat%2Bis%2Bfcr%23.VT06gvnF-So%20%20%20%20%20%20> [Accessed 05/01/2015].

The first cold flush of Rituximab in my arm may have seemed like a momentary symbol of failure, but I forced myself to remember its own place as a game-changing, life-extending drug, access to which patients just like myself had eagerly pursued a decade earlier. A link stumbled across in a support forum thread took me to a Forbes news feature by David Shaywitz<sup>86</sup> telling the story of ibrutinib's unlikely success story. In this narrative of unlikely liaisons, and calculated risk-taking leading to the development of one of the most exciting drugs to impact on the CLL care environment to date, I learned that the Rituximab potentiating the impact of the chemotherapy on my cells was pioneered by biotech company IDEC (merged with Biogen in 2003), among whose founder members was a Dr. Richard Miller. In his role as former CEO of Pharmacyclics, Miller consolidated his interest in B-cell cancers inspired in part by the work of Stanford oncology fellow and CLL specialist Dr. Jeff Sharman (recognizable as a key CLL network actor from this chapter's earlier Translation), with his purchase for a relative pittance of biotech company Celera and its BTK inhibitor (PCI-32765) developed on the back of the Human Genome Project, but with no definitive application to treatment yet established. Readers of this study will by now recognize BTK inhibitors from their previous appearances in perspectives and translations.

Also in the lot was a promising 'tool compound' created by Celera researchers – a molecule capable of binding BTK permanently (covalently), of being fluorescently labelled, and of

<sup>86</sup> Shaywitz is listed on his blog as a Forbes biotech writer, MD, and partner in CATCH (collaboration between MIT and Massachusetts General Hospital to develop a Center for Assessment Technology for Continuous Health). For further biographical details see <https://davidshaywitz.wordpress.com/>

identifying further compounds that could bond BTK tightly but not covalently or permanently. Adopting the unusual model of studying the compound in spontaneously occurring canine lymphomas to circumvent the unsuitability of existing experimental models for these new compounds, early results were only moderately positive. Miller's decision to stick with PCI-32765, because "I have patients in clinic who are dying, and need something right away..." (cited in Shaywitz, 2013a) prefigures what for CLL actors has become history as PCI-32765 now known as ibrutinib rolls out into discourse and treatment across the global networks. A preview of a full report of the RESONATE phase 3 randomized trial of ibrutinib compared with monoclonal antibody ofatumumab authored by John Byrd et al., and published in the *New England Journal of Medicine* in May 2014 concluded that:

Ibrutinib, as compared with ofatumumab, significantly improved progression-free survival, overall survival, and response rate among patients with previously treated CLL or SLL. (Funded by Pharmacyclics and Janssen; RESONATE ClinicalTrials.gov number, NCT01578707) (Byrd et al, 2014).

David Shaywitz's early stage story of ibrutinib peels back some of the layers of activity and associations that underpin the success stories of big pharma, and in doing so reveals some of the economic factors involved from the outset – and some of the points at which the translation could have failed<sup>87</sup>, most particularly the team's ability to recognize and overcome the limitations of experimental models, the value of translational champions on both academic and industry sides (Sharman and Miller), and the element of luck inherent returning successes

<sup>87</sup> Like Latour in *Aramis* (1996), Shaywitz (2012) positions the reader as network actor in this story of successful translations, mediations, and pure good fortune that took the drug ibrutinib to success where Paris's proposed transport system Aramis had failed.

on the risks they took. Shaywitz reminds us how narrative outcomes are always susceptible to some degree of fortune when he says that he could “easily envision how following this exact approach might have led to a far less favorable outcome, and a very different narrative [e.g. ‘cavalier physician imperils patients in reckless pursuit of flawed vision’]” (Shaywitz, 2012).

Miller is a highly significant actor in the world of CLL. Like other key scientists working under the lid of CLL, his name is rarely mentioned in the day to day network discourse, although his contribution as a determined biotech entrepreneur has underpinned the ongoing CLL treatment revolution (and much of the work in this chapter), transforming the lives of many CLL patients and re-shaping the future for many more.

Of equal interest is how much network interest and activity surrounds particular narratives. For example, whilst ibrutinib, its potential side-effects, costs, and availability are among the key discourses in CLL forums over the past two to three years, relatively little debate arises surrounding the political economy driving the industries responsible for innovating and producing drugs. Network actors seeking to read about ibrutinib could easily access this story which was itself told with painstaking attention to associations and translations in the bio-entrepreneurial networks by clinician, scientist, and *Forbes* contributor David Shaywitz. In fact the article was linked into the CLLSA HU forum through a member posting in 2012, yet responded to by only one other member who makes observations about the fragile bonds holding this success story together in its ‘shaky’ journey into the lives of CLL patients and the



bank accounts of the companies innovating it:

A fascinating story which is well worth finding the time to read. Rather sobering to learn that the research knowledge that led to ibrutinib was picked up by Pharmacyclics at zero value and further that animal based research only led to shaky preclinical results (Anonymised CLLSA HU Member).

Nor is it often discussed just how few drugs actually make it from the conceptual stage to prescription. Even with the increased productivity enabled by new biotech tools, there has been no significant change in the approximate 15 year period that it takes for the staggeringly low average of one in every ten thousand new compounds that ultimately makes it through the hugely costly pre-clinical and clinical trials to reach approval (Kessel and Frank, 2007). What's more, if one considers that even among those rare but highly promising drugs with the potential to warrant a human clinical trial, only one in five will eventually be approved and that, according to the Tufts University Centre for the Study of Drug Development (2006) "the average cost involved in the development of a single successful biotech drug is estimated at \$1.2 billion" (Kessel and Frank, 2007), it is a wonder that any novel agents make it to market and into the lives of CLL patients at all.

It seems that some CLL patients are hooked into the importance of getting the black box of this aspect of CLL treatment. The IOB survey results registered just two respondents adding the stock exchange and financial media to their list of sources for information. These network actors went direct to pharma or biotech company trading reports and press releases to stay in

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touch with future developments, watching the evolution of treatments directly through the marketplace:

*I'm not following them very closely at this time as I'm staying so stable. I do also look at some of the biological companies such as Celgene or Biogen. (In Our Blood Survey Respondent 36)*

### **Perspectives: Access to Novel Agents: Trials and Tribulations**

Despite the relatively low levels of detailed attention paid to many of their working practices by patients, the actors in the CLL networks with the most power and influence over the lives of CLL patients and the clinical decisions that affect them are the biotech and pharmaceutical industries and the previous translation shows that, like all other networks, the drug industry is itself a complex array of actors and associations often bracketed or black-boxed in everyday discourse. This perspective will focus now on the process of clinical trials, the more public face of pharmaceutical innovation and a vibrant source of network activity in my research.

Over the course of this study from 2011 to 2015, considerable traffic has been generated in the networks surrounding a number of clinical trials for novel agents and treatment combinations. Patient, clinician, regulatory and industry positions are represented in the circulating stories of drug trials. Keating and Cambrosio (2008) reveal the development and articulation of the components of what they describe as a new style of practice in contemporary trials, evolving on

an ad-hoc basis from post WW2 innovations. These components are identified as “protocols, oncologists, statistics, patients, and diseases” (Keating and Cambrosio, cited in Cantor, 2008:197). Particularly relevant is their observation that the often seemingly ‘mundane’ work of Phase 3 clinical trials (comparing well-known procedures and resulting in incremental improvements in cancer therapy) to some extent ‘buries’ all of the work that has gone before, and will go on after the Phase 3 ‘endpoint’ (*ibid*:223). This chapter has already acknowledged circulating narratives that attempt to make visible the hidden work of pharma/biotech pairings, and as noted in the previous section, it is usually at Phase 2 when a drug starts to provoke significant interest in the networks as a treatment whose potential may be realized in the not too distant future. Phase 2 trials build on Phase 1 work to evaluate the move from in vitro to in vivo, working with larger cohorts of patients with the disease to identify short term side effects before moving into larger phase 3 trials assessing the efficacy and safety of the medicine, and informing the labelling and patient information when the drug goes to market. Phase three trials can be ‘randomized’ as with the UK ‘Flair’ trial currently testing new small molecule drug ibrutinib in combination with rituximab against traditional FCR. Others have ‘crossover arms’ allowing recruits to switch where one drug protocol is clearly producing more effective results. It is also not unknown for randomized trials to be stopped early ‘for benefit’ where overwhelmingly positive results in the trial cohort lead to the assumption that the drug is safe, effective, and that its early release to market would be beneficial to patients.

In January 2014, the phase 3 RESONATE trial pitching oral ibrutinib against IV ofatumumab in 391 relapsed/refractory CLL/SLL patients in over 70 sites across 10 countries was stopped early

for benefit after Pharmacyclics issued an interim trial analysis demonstrating a statistically significant improvement in progression-free survival and overall survival for those patients taking ibrutinib. Subsequently, the Independent Data Monitoring Committee recommended cessation of the trial and the offer to all patients on ofatumumab of treatment with ibrutinib (Chustecka, 2014).

A degree of weighing up potential future issues against current benefits will always be part of a decision to stop a trial early, or to expedite licensing of a drug, which can be contentious in the long run. Bassler et al. conclude that RCTs stopped early for benefit “systematically overestimate treatment effects for the outcome that precipitated early stopping” (2010:1180).

In the US, drugs intended for use either alone or in combination with other drugs to treat serious or life threatening conditions, and showing preliminary clinical evidence of ‘substantial improvement over existing therapies on one or more clinically significant endpoints’ are granted the designation of ‘Breakthrough Therapy’ drugs<sup>88</sup>. This leads to expedited development and review processes, and is roughly analogous to the Promising Innovation Medicine (PIM) designation introduced under the Government’s Early Access to Medicines scheme<sup>89</sup> (EAMS) here in the UK. In the 2014 Medicines & Healthcare products Regulatory Agency (MHRA) document outlining the government response to the latter, regulation, and an

<sup>88</sup> Under section 902 of the Food and Drug Administration Safety and Innovation Act (FDASIA), 2012

<sup>89</sup> On 5 December 2011 the Prime Minister announced a new Strategy for UK Life Sciences, including a commitment to bring forward proposals for an early access to medicines scheme based on the guiding principles that “eligible products will be determined by a scientific opinion that the likely clinical benefits outweigh the risks identified to date where there is high unmet need; NHS funding for product must be cost effective; the UK economy should benefit from the scheme” (MHRA, 2014:2).

urgent need is articulated to reflect the:

profound changes – driven by Genomics, Data, and the rise of Stratified and Personalised Medicines – transforming the drug discovery landscape away from the traditional ‘blockbuster’ model of the post-war years to the world of ‘Translational’ or ‘Experimental’ Medicine in which drugs are designed with and around patients, their data and tissues, in clinical research facilities and hospitals (MHRA, 2014:3).

Interventions such as the 100,000 Genomes Project whose UK roll-out was announced by Chief Scientist at Genomics England, Mark Caulfield on 22<sup>nd</sup> December, 2014 are important contributors to new approaches to research, and have the potential to aid biotech and pharma industries in the task of drug development by increasing the range of data available to them at the r & d phase. The project has the express aim of collecting and interpreting whole genome data across a range of rare and debilitating conditions (including CLL) on an unprecedented scale, and to feed findings back into mainstream healthcare at a rate able to “produce more rapid results for patients” (cited in Genomics England, 2014). Acknowledging the importance of collaborative data sharing in the complicated and fragile translation from ‘molecular insights into useful therapeutic approaches’ to personalized medicine, Park et al. (2004) propose that:

An integrated, collaborative effort is needed among pharmaceutical, biotechnology, government, academic, and patient advocacy groups to translate laboratory insights into rationally designed agents (Park et al., 2004:3885).

The intersection of multiple practices of disease experience is articulately expressed in this call

for appropriate methodologies.

Despite such interventions and aspirations, the question of cost for targeted oncology drugs remains an immediately pressing one. Research and development overheads for oncology drugs are around 20% higher in comparison to the average of all other drugs anyway, and an increasingly competitive marketplace between the growing number of novel targeted therapies that by their very specific nature produce small 'niche' markets (unlike the 'one size fits all or many' nature of traditional oncological drugs) potentially increases the challenge for pharmaceutical companies to actually recoup their large investments in the field of targeted oncotherapies (Tigue et al, 2007:2).

The promise of a patient databased world of experimental medicine emerging from the traditional lab-based 'blockbuster' model of drug research clearly anchors clinical contexts to the economic and cultural models of contemporary drug production and it is vital to explore to what extent networked patients are aware of and engaged in these debates. For example, resistance to the EAMS scheme based on the UK's Faculty of Public Health (FPH) concerns that there is "no substantive research that allowing medicines into the market place earlier" would benefit improvements in population health, and that reduced requirements for evidence could be exploited by the pharmaceutical industry keen to extend the potential revenue generating life of a drug by up to a third through accelerated progress through the trials process (Pharmaphorum, 2014; Skipla-Serry, 2013).

Despite these seemingly rational concerns, I was unable to locate any such caution in the central hubs of the CLL networks, where the concerns of the FPH put forward in the consultation period of the EAMS scheme seem largely to be overridden by enthusiasm for early access. After all, where traditional treatments bring enough of their own dangers, and people are running out of options, individual perceptions of risk are likely to differ from the broader discourses of government health bodies.

## **Perspectives: Online Narratives of the Price of Drugs**

Whatever the trial type, it is clear that successful transition to trial for novel agents begins a new and more public narrative phase in the networks. It is at this point that patients begin to interface directly or indirectly with the drug itself, and with its narrative trajectory into the disease community. Issues of access to trials and expedited access to drugs through Breakthrough Therapy or Promising Innovation Medicine designation as a result of successful early data are a dominant theme among patient group narratives, again often accompanied by concerns surrounding cost. After being granted 'breakthrough status' by the FDA in the US in 2013 for the treatment of CLL, SLL and Mantle Cell Lymphoma, Pharmacyclics and Johnson and Johnson set the tariff on their novel agent Imbruvica (ibrutinib) at over \$90 or £58 per tablet, bringing the annual costs for a CLL patient to around \$98,400, or £63,500 (2014 conversion rates) *before* the added costs of adjunct therapies.

In the UK, the National Institute for Health and Care Excellence (NICE) is responsible for making decisions about which drugs the NHS will routinely fund (under the broad umbrella of the ??? in Europe, and the job of the FDA in the US). The cost-benefit calculations required to underpin these decisions on a regular basis by NICE are based on a unit of measurement referred to as a QALY – a ‘quality adjusted life year’, gauging a drug’s effectiveness in relation to the cost of a year of healthy life. The ‘quality adjusted’ element of the tool evaluates justification for funding through *improving* life even if not prolonging it. As noted, the cost of many of the newer cancer drugs places them outside the NHS reach. If we consider however that NICE sets a limit of less than £20,000 to £30,000 per Qaly (with almost a 100% hike for some end-of-life drugs), the price tag attached to novel agents such as ibrutinib place them way outside the budget (Cook, 2014).

In England (specifically), the Cancer Drugs Fund (CDF) was set up by former Health Minister Andrew Lansley in 2010 in political recognition of this fact to help fund equitable access to expensive cancer treatments across English NHS trusts. The CDF (estimated to have treated some 55,000 patients with drugs falling outside of NICE’s benchmarks of cost effectiveness) announced in November 2014 that, despite being given a 40% increase in funding for the next two years from £200m to £280m a year, financial restrictions would mean removing from its list any drugs that are overpriced or of questionable clinical benefit<sup>90</sup> (Hawkes, 2014:349).

<sup>90</sup> The ultimate decision to remove a number of blood cancer drugs from the fund was met by disappointment and anger across the CLL networks. Professor Chris Bunce, Research Director at Leukaemia & Lymphoma Research, said: “We are very concerned indeed that so many drugs for blood cancers like leukaemia, lymphoma and myeloma have been delisted from the Cancer Drugs Fund. The decision to remove effective drugs from so many



In September, 2014, a private posting on the Health Unlocked site about the CDF linked readers to a BBC report by BBC flagship news programme, *Newsnight*'s Policy Editor, Chris Cook. Entitled 'How Much is a Year of Life Worth?', the report opens by directly addressing readers as taxpayers and asking them to consider in relation to the decisions made by NICE on their behalf, just how much how should "you, the taxpayer, be willing to pay to keep someone alive? (Cooke, 2014: no page). Given the statistical spread of cancer across the UK population (stats), many tax-paying readers of the article across the general population will either have direct or family-related experience of cancer, so the "someone" in the question may not turn out to be as impersonal or detached as it may initially sound. Cooke asks the question whether the CDF by its very existence ultimately encourage corporate pharma to retain high drug tariffs, an issue also addressed by John Appleby, Chief Policy Editor of the Kings Fund (2014), alongside his consideration of the mind-melting moral maze constructed by the cause and effect considerations required to fully understand the implications of using 'qalys' to measure cost-effectiveness:

The corollary of this is that the true (but hidden) cost of the CDF is not the £280 million financial value of the fund itself, but rather the value of the forgone benefits (lives saved, pain averted, QALYs gained etc.) if the money had been spent on other patients (Appleby, 2014).

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patients represents a dramatic step backwards. Many of these treatments can significantly prolong survival times and provide a good quality of life for diseases that can have devastating symptoms. In many cases, patient populations for the drug indication are very small, so the total cost burden to the NHS is actually relatively low. See staff post 'RESPONSE TO THE REMOVAL OF BLOOD CANCER DRUGS FROM THE CANCER DRUG FUND' on the Leukaemia and Lymphoma Research website, 12<sup>th</sup> January, 2015 for the full response from this influential organization.

Translated in this way, the calculation is nigh on impossible, but it is a sobering thought that the cost of the CDF extends way beyond the simple financial matter of 280million pounds. The impact of this on the lives of other patients is rarely, if ever, raised as an issue in the CLL networks when anxiously awaiting CDF decisions about funding CLL related drugs. Perhaps a degree of self-interest is inevitable among patients facing down any potentially fatal disease, but it is also the case that where broader contexts are not addressed due to a lack of understanding of process/economics, more fulsome discourse surrounding the wider socio-cultural impacts of disease-specific issues is obstructed. Meshing disease community networks into the political and economic networks that influence choices has the potential to raise fundamentally political questions about how we manage the complex interrelationships, as the following translation exploring CLL Topics as a locus of advocacy for early access to ibrutinib in the case of patients with few options demonstrates.

## Translation: Advocating for Compassionate Access Online (CLL Topics and Compassionate Access for Ibrutinib)

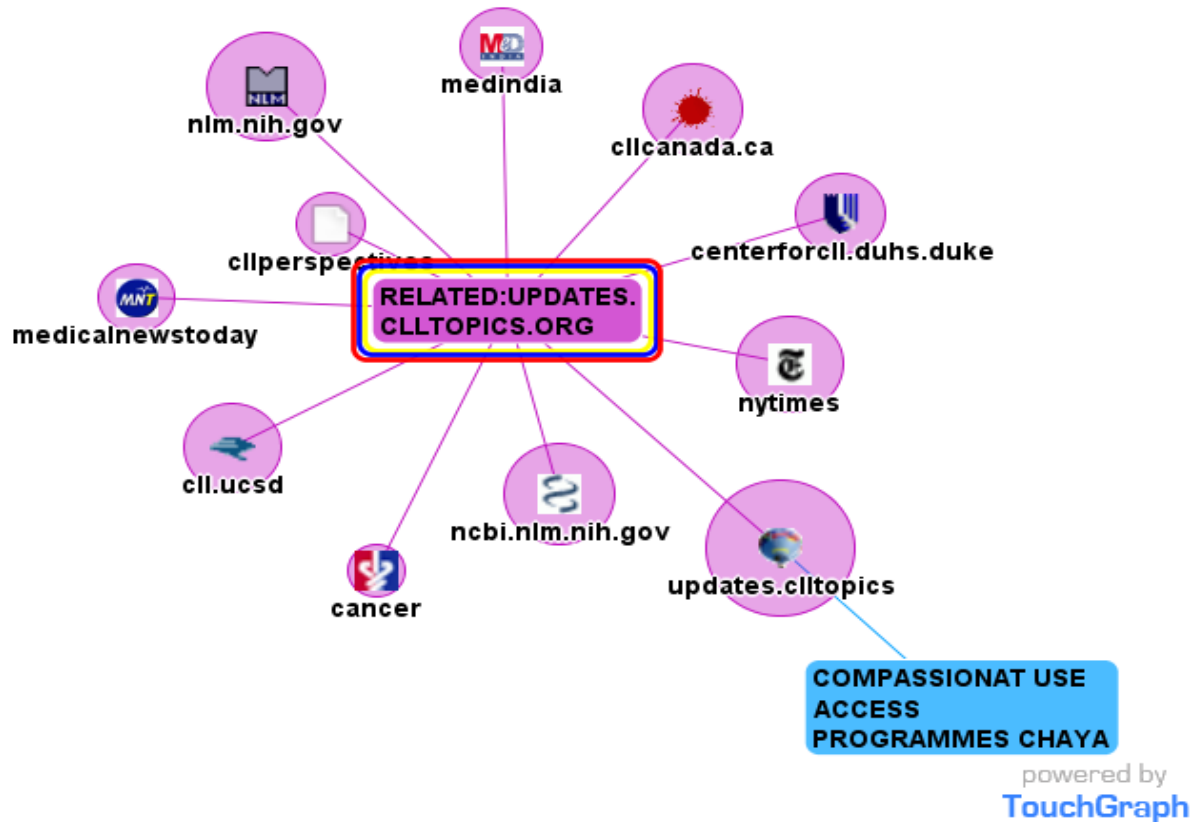


Figure 36: TOUCHGRAPH (2015) network connections to Chaya Venkat's post on compassionate use access programmes for ibrutinib [Network Map]. [Online] Available at: <http://www.touchgraph.com/seo/launch?q=cllsa%20uk%20health%20unlocked> [Accessed 05/01/2015].

If we follow ibrutinib through the networks an interesting story of a drug's entry into a disease community emerges to underpin further exploration of the role of patient and clinician advocacy in gaining access to new drugs moving slowly (and expensively) through the pipelines

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of development and regulation. In February 2013 in the US, Pharmacyclics announced that ibrutinib had been granted breakthrough designation as monotherapy for the treatment of CLL (Asco Post, 2013).

Just five months earlier on September 19<sup>th</sup>, 2012, Chaya Venkat writes about the exciting potential of ibrutinib even for those patients with the high-risk 17p deletions. The drug was at the point of its developmental phase where phase two trials were full, and phase three trials (randomized into two arms in many cases) were only just opening, with long lists of inclusion criteria limiting applicants, and Venkat forcefully articulates the human pain and frustration behind the struggle to access novel therapies in their early stages:

I have had to face this heartbreaking question several times in the past few months: what do I tell patients with aggressive CLL with the 17p chromosomal deletion, who cannot get into one of the ibrutinib trials underway, and who cannot afford to wait for future trials and definitely cannot wait for the drug to become commercially available? This drug may give them a much needed lifeline, perhaps set them up with a good enough remission that allows them to get into a transplant program. Or it may give them a couple more years of high quality of life with their families. Who can put a dollar value on that? (Venkat, 2012)

As previous translations have shown, Chaya Venkat's (now dormant) site CLL Topics was very much driven by an ethos of advocacy. We learn from the page that Johnson and Johnson have already tapped into the potential data collecting potential of patient advocacy sites such as CLL Topics by contacting Venkat to discuss the possibility of a collaborative survey of CLL patients along the lines of a prior survey with the Mayo Clinic into the quality of life for 1482 CLL

patients conducted between June and October 2006<sup>91</sup>. We also learn that Venkat took the opportunity to lobby the company for compassionate access to ibrutinib in her response, and the extract she provides on the site from her letter gives the reader a perspective into a potential model for productive relationships between pharma companies and patient communities:

Well-publicized compassionate use access programs are a hugely important way of reaching out the patient community, a way of establishing good faith on behalf of the pharmaceutical company. J&J is a large company, with the human and financial resources needed to manage such a program, a corporate culture that does not look only at profits or stock price. If anyone can take the lead in establishing a badly needed new paradigm for working with the patient community, it is going to be companies such as J&J (*ibid*).

Venkat's report back on the response from J & J at the time took the form of resigned acceptance to their refusal to acknowledge her request: "The perfunctory brush-off I got is nothing personal, I am well aware of that. But it is one more sour note in the long story of pharmaceutical industry's inability to establish good-faith and two way communications with the very patients that they will be marketing to down the road" (*ibid*). Twenty six responses totaling just over 3,100 words from the CLL patient/carer community agree with her, including those already fortunate enough to have accessed trials through the traditional route and expressing their frustration that others too could not benefit from a drug as life-changing and as effective for certain patient groups as ibrutinib.

<sup>91</sup> Results of this survey were written up in Shanafelt's (2007) paper, 'Quality of life in chronic lymphocytic leukemia: an international survey of 1482 patients', published in *Br J Haematol*. October, 2007. This paper has been referred to several times in this work.

Although doubtless too late for some patients, just two years on at the time of writing, we know now that the trials Venkat refers to were stopped early and FDA approval for relapsed and refractory CLL granted early. Ibrutinib was approved in US for previously treated CLL patients in February, 2014. It was approved in UK (and rest of EU) in October 2014 for MCL (mantle cell lymphoma), or patients with CLL who have received at least one prior therapy, or first-line in those with the chromosomal abnormalities deletion 17p or TP53 mutation. Its journey through the licensing process can be seen documented on the NHS pharmacy based UK Medicines Information site, publically accessible and demonstrative to those interested readers of the complexities, nuances and time frames involved in the passage of a drug through phase 2 and three trials to market (UK*mi*: no date).

In the meantime, and for patients unable to access trials, compassionate access programmes for ibrutinib were eventually instigated both in the US and UK. A Janssen press release by Chloe Dix for Reynolds Mackenzie published on *Pharmaweb* on 19<sup>th</sup> December, 2014, documents the successful launch of ibrutinib in the UK and quotes Janssen M.D., Mark Hicken, stating his company's apparent dedication to making the drug accessible to as wide as possible a range of patients through their appeal to the NCDF to support funding of the drug in England:

Janssen is working to bring new therapies to patients living with complex and challenging-to-treat blood cancers. We are dedicated to ensuring that patients suffering from chronic lymphocytic leukaemia and mantle cell lymphoma have access to ibrutinib and we have therefore submitted an application to the National Cancer Drugs Fund to ensure eligible patients in England can access this advancement in the treatment of blood cancer (Hicken, cited in Dix, 2014).

As Dix points out in her closing paragraph, “About 600 UK patients with CLL have already received ibrutinib via a Named Patient Supply provided by Janssen at no cost to the NHS”. However, access to the compassionate use programme ended in September, 2014. This study has already drawn attention to the current pressures on the NCDF and its aims to streamline and cut costs accordingly, and to the staggeringly high price tag attached to ibrutinib at over £80,000 a year, so a positive response to the application was by no means a given<sup>92</sup>. Two other drugs targeting CLL are included in the list of revisions and additions, including novel agent idelalisib to be administered in conjunction with anti-CD20 antibody based agent Rituximab (in place of cytotoxic drugs for certain refractory patients), and changes in the protocols for bendamustine for CLL patients (NHS England 2015).

It is also significant that, whilst the CDF has approved funding for use in England, its appraisal with NICE for generic NHS approval is still in process at the time of writing. Online CLL support community responses to this news provide further evidence of narrative circulation and sharing in the context of CLL treatment as a regulatory issue intersecting with clinical perspectives on the future of new treatment protocols. This is beautifully demonstrated in a posting made by CLLSAUK member and active network contributor Hairbear who, as part of an ongoing thread on the progress of ibrutinib in the US and Europe offers updated information on the CDF decision and the position of the drug in relation to NICE approval, also linking members out to 2 videos from a US panel discussion on the future of CLL treatments among CLL expert clinicians

<sup>92</sup> I am now in a position to update this speculation with a firm decision from the CDF on 12th January, 2015 to fund ibrutinib for those patients with refractory CLL, failing to respond to CIT, experiencing a progression-free period of less than three years, or considered too old or unfit to withstand CIT.

(Onc Live Peer Exchange<sup>93</sup>).

Hairbear offers members the opportunity to engage with the interesting peer debates contained in the videos concerning when and whether to stop ibrutinib treatment, and discussing the continuing benefits of 'one-off' six-monthly FCR treatments (as opposed to ongoing treatment with novel agents such as ibrutinib) for certain patient groups (younger, fitter, 13q deleted), the pros and cons of discontinuing CIT early in the presence of positive responses, and research comparing less toxic alternatives to FCR such as BR (bendamustine and rituximab). All of this he states that he finds reassuring, "knowing that front line use of novel therapies or novel therapy combos will not come available to treat the fitter younger group outside of trial for quite some time and FCR and BR are the NHS available options for UK patients in this group" (Hairbear, 2015: CLLSA UK). The regulatory decisions of the CDF, and anticipation of those of NICE in a UK setting are intersected here with the broader global debates taking place about treatment protocols, new, old and hybrid.

As Hairbear himself reports, others living with CLL in the networks may well find exposure to the way in which these multiple practices of their disease intersect to some extent reassuring. "I can't access ibrutinib and I want it" may, in some circumstances at least (i.e. for the non-refractory, and generally otherwise healthy) becomes less of a *definitive* rallying cry of loss or exclusion for patients exposed to an understanding of the regulation and economics of drug

<sup>93</sup> CLL specialist Drs. Kipps, Bird and Furman discuss the changing landscape in a YouTube video posted on the OnLive TV channel. 'Selecting First-Line Treatment for Chronic Lymphocytic Leukemia (CLL)'. Online (OnLive, 2015).



development and licensing, the trials process, and the limits of knowledge in relation to immature data surrounding novel agents. For others however, inability to access novel agents may well be a case of life or death as the following perspective attempts to show. However, those patients for whom access to any of the twenty five other drugs *dropped* by the CDF in the same evaluation round announced in January, might have made a tangible difference to their futures need to be kept in mind. It remains impossible to speculate whether exposure to similar versions of their own disease contexts would prove equally reassuring or otherwise. Gains for some patients inevitably translate to losses for others in a cash-limited treatment fund and disease specific research of this nature might have a useful role in exploring the implications of that through tracing circulating narratives in other disease networks.

## **Perspectives: Counting the Cost of Unequal Access to Novel Agents in Human Terms**

Keeping cancer patients alive is, as we are becoming aware, an increasingly costly business, particularly as novel agents make their way out of the clinical trial's process and onto the tariffs of the insurance companies and healthcare budgets required to fund them. Decisions about meeting costs where resources are finite ultimately come down to issues of perceived value, which will vary according to the perspective of the inquirer. In relation to cancer drugs, Tigue et al. (2007) sort patients, physicians, policy makers, insurance providers, and pharmaceutical manufacturers into the wider perspectival categories of 'societal', 'patient' and 'payer', pointing

out that, despite their undeniably positive outcomes for patients, the current high tariff of novel agents is proving unsustainable against a backdrop of soaring healthcare costs<sup>94</sup>. Such drugs produce costly side effects, themselves responsible for significant healthcare expenditure<sup>95</sup>, and are often administered along with already expensive therapeutic agents such as rituximab for example. Outside of these concerns, the global playing field for decisions concerning access is not a level one though, and that means some patients may be suffering or dying from restricted access while others aren't.

In their (2006) pan-European comparison regarding patient access to cancer drugs, Nils Wilking and Bengt Jönsson refer to this as “the reality that cancer patients in Europe do not have equal or rapid access to cancer drug therapies” (2006). This chapter has already focused sharply on the vagaries and frustrations of access to novel therapies, outlining the potential physiological and psychological impacts for those caught in the regulatory and market-driven interstices of traditional/new treatment approaches. As Chaya Venkat's CLL Topics translation shows, this is not just a case of frustration and envy for those unable to access new drugs. In his foreword to Wilking and Jonsson's report, President-Elect of the Federation of European Cancer Societies, John F. Smyth makes this simple but powerful assertion:

The essential facts are: cancer is a significant cause of morbidity and mortality in Europe, and scientific advances have given us the potential for more treatment approaches than are currently provided. New medicines have no benefits unless they

<sup>94</sup> That saw the total cost of cancer care in the US alone in 2005 set at \$209.9 billion and rising. (Tigue et al., 2007)

<sup>95</sup> – measured in terms of time lost during the first year of cancer treatment – produce indirect costs of around \$2.3 billion dollars in the US alone (*ibid*)

are used by the patients who need them, and the need to balance benefits, costs and available resources should not prevent patients from gaining access to novel drug therapies (Smyth, 2006, cited in Wilking and Jonsson: foreword).

In his analysis of access to cancer drugs in the USA, Dr. Frank Lichtenberg of Columbia University equated access to more cancer drugs with improved survival rates for patients, citing a 50-60% increase in survival rates in the first 6 years post diagnosis in relation to an increased stock of available cancer drugs (*ibid:3*). Furthermore, Lichtenberg correlates an increase in the number of available drugs across Europe and the US with an increase in survival rates at both one and five years, concluding that “it is clearly in the best interest of cancer patients that new, innovative drug therapies are made available to them as soon as possible. Reduced or delayed access to cancer drugs has a very real impact on patient survival” (cited in *ibid: 3*). But delayed access is a very real issue, happening to very real patients, as this work has shown in the case of CLL.

Wilking and Jonsson identify a number of key themes reflecting those already addressed in this chapter, such as “research funding, the drug approval process, the role of health economics [including health technology assessments and economic evaluations<sup>96</sup>] and budgetary issues limiting the uptake to new drugs” (*ibid: 3*). Economic evaluations tend to follow a monetary cost/benefit analysis model of evaluating the ‘cost-effectiveness’ of new drugs that Wilking and Jonsson argue should account for the *total* economic impact of a new drug therapy (long term

<sup>96</sup> Health technology assessments and economic evaluations can represent a significant hurdle to patients accessing new drugs, having earned the title of the ‘fourth hurdle’ in this context.

likelihood of relapse, patient ability to work through treatment and return to productive life beyond treatment, and so on), instead of a singular focus on the cost of the drug to a specific healthcare budget at a specific chronological point (*ibid*: 5).

The report notes an interesting anomaly in relation to the UK that, despite ranking highest in Europe in terms of direct cancer research funding (with charities contributing more than the government), currently lags behind other EU countries in terms of patient ability to access new cancer drugs. The authors go on to point out that the UK is more susceptible to the role of economic evaluation than anywhere else in Europe, guidance issued in England by the National Institute for Health and Clinical Excellence (NICE), in Wales by the All Wales Medicines Strategy Group (AWMSG), and in Scotland by the Scottish Medicines Consortium (SMC).

A favorable evaluation for a new treatment from NICE should in principle accelerate and broaden access to the drug, but growing workloads impact on the institute's capacity to handle evaluations in a reasonable timescale. According to 2015 guidelines, the minimum timeline for seeing a drug through the appraisal process with NICE is around ninety weeks (see Appendix 13: for diagrammatic timeline). During any delay period, allocation of budgetary resources to new drugs is frozen consequently further delaying innovative treatments from entering the healthcare system and the lives of cancer patients in England which could potentially be saved, extended, or improved by them. Patient access to novel therapies is highly contingent on financial resources and the politics of funding allocation within the healthcare systems at any given time. Wilking and Jonsson make it clear just how contingent access to innovative cancer

therapies can be on broader political gestures concerning healthcare expenditure policy: Although cancer drugs account for less than 10% of the total healthcare expenditures for cancer and represent 3.5-7% of the total drug costs, they are an easily identified target. In efforts to manage healthcare or budgetary costs, healthcare policy and decision makers may therefore seek to delay or restrict access to these new innovative drugs. Such actions have very real impact on survival rates (Wilking and Jonsson, 2006: 5).

Of course, the time consuming process of a convoluted evaluation doesn't automatically equate to a drug being accepted, as demonstrated in October 2014 when Roche's monoclonal antibody treatment for CLL, obinutuzumab, (marketed by Roche as gazyvaro) was rejected for frontline CLL treatment by NICE on the following grounds as reported by Ben Hirschler for Reuters: "Although obinutuzumab is a clinically effective treatment, there were too many uncertainties in the company's submission and we cannot be confident that it is an effective use of NHS resources," said NICE's chief executive, Andrew Dillon" (Hirschler, 2014).

This news quickly found its way into the support networks, heralded by a private member posting on CLLSA Health Unlocked and linking members out to the Reuters article from which the above quote is extracted, and to the official announcement on the NICE site. The member responsible for posting the original comment and the main contributor to the ensuing debate are both highly active actors in the CLLSA network, often responsible for introducing news to the site about trials and the drugs development process for relevant CLL drugs. They demonstrate the important role played by the highly informed members of support networks in

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increasing the hypertextual network vibrancy of these narrative nodes, and contributing to the knowledge and understanding of the broad range of processes and actors underlying issues such as access to novel agents for cancer patients, the quality and duration of whose lives may depend on them.

Update posts on gazyvaro indicate that it was approved in December 2014 for frontline use combined with chlorambucil in fludaribine unsuitable patients by the SMC (Scottish Medicines Consortium), and in Switzerland for the same indications in June, 2014. The difference in tone and attitude to the drug's effectiveness between the NICE recommendations for use in England (see previous quote), and the Roche press release following approval success in Switzerland are worth considering:

Marketing authorization for Gazyvaro was granted on the basis of the results from the Phase 3 study CLL11, which showed that patients treated with Gazyvaro and chlorambucil-based chemotherapy had a 61% lower risk of disease progression or death compared with the current standard therapy comprising MabThera [rituximab]and chlorambucil (Roche Switzerland, 2014).

Alongside the information included in the press release that due to favourable comparisons with existing therapies of its clinical benefits for certain patient groups "Gazyvaro has become the first medicine in the world to be designated as a Breakthrough Therapy by the US health authority FDA" (*ibid*), patients in the network may remain confused by the nature of the 'uncertainties in the companies submission' (Dillon, cited in Hirschler, 2014) articulated by NICE CEO Andrew Dillon in the institute's December, 2014 rejection statement for the drug.

## **Perspective: Narrative Networks and trials Participation (Patient Attitudes to Trials)**

Founder of online support site 'Lymphomation', Karl Schwartz made a plea on the site in 2013 for funding to increase lymphoma patients' involvement in clinical trials after noting a drop in trial interest and uptake in patients polled from 27% in 2009 to 12% in 2013 (Schwartz, 2009). Seeking further information to identify obstacles for the 2013 respondents, Schwartz notes that the (126) 2009 survey patients who declined trial participation after consideration identified the following factors as contingent on their decisions: "Randomization (70), Insurance (49), Study Risks / Toxicities (42), Travel and Lodging (30), Eligibility (28), Tests and Procedures (12), and a perception that Regular Treatment is superior (6)" (Schwartz, 2009). Randomisation is by far the biggest obstacle identified in this group, with patients seemingly unhappy to cede control to chance when the stakes are so high.

Also significant in trial involvement is the inclusion of trials for consideration in pre-treatment discussions with a Consultant. In the 2009 study, of the 112 (45%) patients whose consultants had discussed trials with them, 95 (85%) answered that they would consider a trial, and 59 (53%) participated in trials (Schwartz, 2009: abstract, no page). In 2013, only 15 (12%) of patients said their consultant has discussed trials with them, perhaps contributing to the very low recorded involvement figure of 12% trial involvement. This omission of trials from pre-treatment conversations is not confined to haematological cancers alone, with less than 5% of

adults with any form of cancer participating in trials. According to Cameron Scott of Health Information aggregation site 'Healthline', this is not a simple case of too many patients for too few trials. Between 2000 and 2007, over two in ten National Cancer Institute (USA) sponsored trials significantly under-recruited, one in ten trials closes due to lack of participation, and nearly 40 percent of all cancer trials failing to complete do so because of low patient participation (Scott, 2014: Part 1).

Although CLL patients in the support networks express a degree of trepidation about some elements of trial participation, there is a general sense of a desire to seize perhaps the only current opportunity to access the novel agents being evaluated. Brian Koffman draws attention to the fact that the accrual rate for trials of novel CLL agents is generally high, with some of these trials filling at record rates (Koffman, 2013), but there is a clear advantage for those patients treated by research-active clinicians, and/or already hooked into information circulating in online networks. The worry is what happens to those patients solely reliant on their Doctors for information and encouragement to exploit the treatment potential offered by trials.

So why are doctors not doing more to encourage their patients into the trials process? As noted previously, everyday time and financial constraints can place very real obstacles in the way of patient education in clinical contexts. Patients who are unaware of trials as potential treatment options face less choice and opportunity than those who have either researched trials for themselves or had them suggested by their doctors. As this work has already demonstrated, it



is too reductive to read this solely as the responsibility of negligent or uncaring clinicians overlooking their patient's needs. Deputy chief medical officer at the American Cancer Society, Dr. Leonard Lichtenfeld believes that, in the face of the devastating nature of cancer "Doctors are doing the best they can and for whatever reason they don't know about trials," (Scott, 2014: Part2). A trial system that places the emphasis on already over-stretched clinicians to keep up to date with ongoing trials, screening, and consent processes can have a significant impact on the planned timeline of patient flow through clinics. As clinical oncologist and researcher, Dr. Ajai Chari puts it, "Unless you have a vested interest as a clinician, you're not going to find the time" (cited in Scott, 2014: Part 2). What might constitute those 'vested interests' is an important issue in understanding clinicians' motivation to encourage patient involvement in the clinical trial process.

## Translations: CLL Specialists Encourage Trials Participation (Patient Advocacy Video from European Haematological Association Conference Milan, 2014)

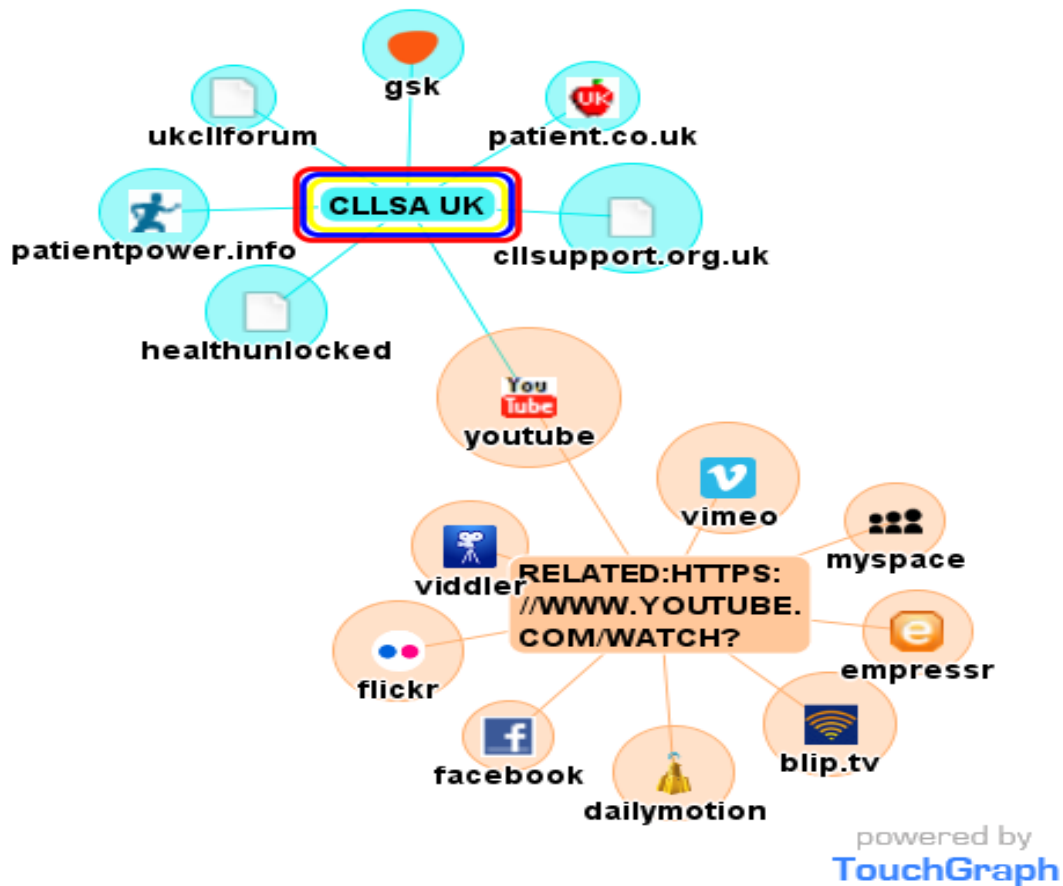


Figure 37: TOUCHGRAPH (2014) network connections to 'Positive News & Developments When Treating Chronic Lymphocytic Leukaemia' video from European Haematological Association Conference in Milan, 2014 [Network Map]. [Online] Available at:

<http://www.touchgraph.com/seo/launch?q=https%3A%2F%2Fwww.youtube.com%2Fwatch%3Fv%3DSxYBcO9Y8VQ> [Accessed 10/01/2015].

In a video made at the European Haematological Association (EHA) meeting in Milan, 2014, and posted to CLLSA UK's YouTube channel, viewers see three leading UK specialists, Professors

Pete Hillmen, Simon Rule, and John Gribben actively encouraging patients to canvass their own doctors about available trials. Professor Hillmen, working out of Leeds, plays a leading role in heading up UK CLL trials, and describes a number of trials for novel agents in detail in the video. Professor Rule from Plymouth, specializing in mantle cell lymphoma, and instrumental in early UK work with ibrutinib, talks of the contemporary treatment landscape as a ‘fascinating’ time for CLL patients who are faced with a number of ‘game-changing’ compounds as alternatives to traditional CIT rolling out in pivotal trials in the UK. Figure 37 is a screenshot from the video showing Professor Rule appealing directly to patients to “ask the question – where is this available, and can I be considered?”

Image removed due to copyright restrictions

**Figure 3812: CLLSA UK (2014) ‘Positive News & Developments When Treating Chronic Lymphocytic Leukaemia’ video filmed at the EHA meeting in Milan, 2014 [Screenshot]. [Online] Available at: <https://www.youtube.com/watch?v=SxYBcO9Y8VQ> [Accessed 07/09/2014].**

Professor John Gribben, working out of Barts Hospital in London, and previously explored as a network actor in the diagnosis chapter of this work, advances the rhetoric of patient advocacy in the video. Gribben points out the importance of patient participation and involvement in decision making about treatment, stating that this involvement is “important in terms of lobbying for access to some of the impressive agents being developed”, and acknowledging the importance of CLL patients being “more empowered” in the face of potential economic challenges to accessing new drugs”. The excitement is tangible among these three leading haematologists, but perhaps more encouraging is the active canvassing of patient participation in trials and political involvement in issues of access. The ‘vested interest’ so integral to clinicians’ motivation to make time to speak to patients about trials is clearly evident in these three highly research-active clinicians, but for patients treated by non-specialists in smaller regional centres, outside of the major research nodes, this degree of clinical motivation, or indeed awareness of the up to date trials landscape, may not be integral to discussions concerning potential treatments. In those cases, the sharing of videos like this in the networks could be a significant factor in raising patient awareness of the potential to apply for relevant trials, and even to lobby for access to drugs.

In bringing such discussions to the clinical table, patients might in turn expose busy, general haematologists to cutting edge specialist CLL research and trials information. This video was screened to around 120 CLL patients and carers at a face to face CLLSA patient meeting in Cambridge as well as being posted on CLLSA’s YouTube channel, and linked out into the global community via the health unlocked site. At the same meeting, a panel of CLL patient advocates

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chaired by Andrew Schorr, included a member of CLLSA active in lobbying for access to CLL drugs, and seeking support and involvement from the CLL community present. Many of the CLL patients and carers in the audience were not already aware of the channels through which patient advocates might campaign for access to novel agents prior to the meeting.

As demonstrated by Schwartz (2013) in his work on attitudes to trials among lymphoma patients, the issue of randomization is a major block to patients. With many of the recent trials for CLL novel agents, there is no other way to access the desired drug outside of trials, and the non-preferred treatment of the control arm tends to be the traditional gold standard for the particular disease profile being tested anyway. However, it is sometimes the case that patients don't have a thorough understanding of the randomization process, therefore not making fully informed decisions, but rather ones based on emotional responses or gut-feelings.

As Scott (2014) points out, researchers and patient advocacy groups observe that often patients are worried about participating in randomized trials in which they fear they might be given a placebo. Once again, poor medical literacy emerges as a powerful obstacle to patient empowerment, and is clearly demonstrated in the following comment from an IOB survey respondent who, despite making active steps towards engagement through the networks, remains unable to understand much of what they read:

*Healthunlocked and CLLtopics are my main sources of information. I follow all links to learn more. Frankly so much of what I read is so afar above my ability to understand and remember I feel all I accomplish is to be aware. I am acrid [sic] of clinical trials because*

*of the risk of getting a placebo and not the actual trial medicine (IOB Survey Respondent 151).*

Reticent about trial involvement based on the risk of being given a ‘placebo’ instead of ‘the actual trial medicine’, this respondent shows a poor understanding of phase 3 trials procedures for cancer drugs which would not be set up on a placebo v trial drug basis, rather an existing and provenly effective cancer drug v trial drug. The need for further research into ways of improving medical literacy in online disease networks already addressed in this work is fundamentally important in relation to trials knowledge and awareness as new drugs with the potential to change outcomes for the better emerge through the trials system.

Also of interest are Brian Koffman’s views on cultural attitudes to randomization. In a 2014 blog entry exploring a paper given by CLL specialist Professor Hallek at the iwCLL 2013 (international workshop on CLL) in Cologne, Koffman draws attention to Prof. Hallek’s failure to address European patients’ greater willingness to participate in randomized trials demonstrated in the generally lower accrual in US trials having two or more randomized arms. This Koffman attributes to the fact that “Canadians and Americans prefer more control in deciding their therapy” (Koffman, 2014: no page).

Even where patients have a good grasp of the trials process, and are well-informed either by their clinicians, network activities, or both, it would be wrong to assume that trial participation is a straightforward decision to make. As the Lymphoma Research Foundation’s chief program,

policy, and communications officer, Meghan Gutierrez points out in relation to trial participation, and the hotline the foundation has set up to educate patients about trials, “It’s one thing to think of it in the abstract and quite another when you have received a potentially life-threatening diagnosis and are thinking about the ways in which you’re going to treat your disease” (Gutierrez, cited in Scott, 2014: Part 3). Arguably then, it is times when patients are most likely to be dealing with potentially overwhelming emotional responses to their diagnosis, or disease progression that well-informed, rational debate surrounding their treatment choices, including the possibility of joining a trial, is most important.

As I have attempted to show, outside of the vagaries of the pharma/biotech industries and the inconsistencies of the regulatory bureaucracy of drugs development across the globe, a significant element of successful access to new drugs depends on patient knowledge. Knowing what trials are available and where, understanding inclusion criteria and being able to relate that to their individual disease profile, and having some awareness of the trials process alongside other possible access routes are all fundamentally important in increasing an individual’s chances of accessing novel therapies.

Encouraging patients to ask about trials is an excellent way of sparking patient involvement in managing their own care. Appendix 14 analyses a posting by key CLL network actor Hairbear, employing the ‘It’s OK to ask’ campaign<sup>97</sup> to encourage CLL patients specifically to get involved

<sup>97</sup> In May, 2014, the National Institute for Health Research (NIHR) marked International Clinical Trials Day with the launch of its UK ‘OK to ask’ campaign promoted across national mainstream and social media, and encouraging

in trials. It demonstrates how the kind of advocacy for patients to seek out trials encouraged by doctors such as Simon Rule, Pete Hillmen, and John Gribben in the EHA video explored in the previous translation is reflected in national campaigns, and picked up by key patient/actors in disease-specific support communities online. More work is needed however to assess the degree of confidence and medical literacy surrounding their disease required by patients in order to feel comfortable enough both to ask about trials, and also to gauge the response of those clinicians not already engaged in this dialogue with their patients.

## **Perspectives: The Networked Trial Community**

### **Patients are doing it for themselves? Advocacy Groups and the Pharmaceutical Industry**

This exploration of trials in the CLL networks concludes by looking in context at the ways patients use network activity in relation to trials. This includes patients working *alongside* pharmaceutical companies to advocate for access to drugs, and patients using online networks to collaborate and communicate with each other during trials with a number of implications that I will explore in this section.

The chapter has already introduced readers to engaged clinicians actively canvassing patients to enter trials, and even to lobby government and industry for access to the novel agents that

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patients to ask their doctors about the availability of current treatment trials for their particular disease. This underscores a sense of access to trials as a right for patients, and one that they should actively seek.



might change their lives. The role of support communities in circulating information about trials and access to drugs has also been highlighted. It remains true however that, despite the emergence of informed patients actively engaged with the drug development and licensing process, control over what drugs are made available and when still lies largely with the pharmaceutical industry and the relevant regulatory and policy institutions. Where compassionate or early access is not already a possibility, it may be incumbent on patients (and their physicians) to lobby directly for access. This short sub-section explores how patient advocacy groups are working together with big pharma to improve access and information, often aided by online networking among patient groups. Importantly, I seek to explore the nature and power dynamics of that relationship as the networked patient (and their data) becomes more and more potentially valuable to the pharmaceutical industry.

This work has set out to argue that as informed networked patients become increasingly exposed to the narratives and cultures of a range of practices and institutions concerned with their particular disease they are better prepared to collaborate effectively with them. For example, independent patients, organized patient advocacy groups, and the pharmaceutical industry itself now collaborate across a number of phases of the drug development process, from research funding, to trial design and recruitment, and active lobbying for approval and access. The previous perspective demonstrates how a CLL patient group utilizes face-to-face meetings alongside online networks to raise patient awareness of direct lobbying of government in terms of regulation, and the pharmaceutical industry in relation to drug tariffs.

Pharmaceutical companies themselves of course are well aware of the benefits of relating to patient advocate groups, many employing their own patient advocate representative. Thomas Sellers, cancer survivor and Senior Director for Patient Advocacy and Corporate Philanthropy at Millennium: The Takeda Oncology Company, told the *ASCO Post*<sup>98</sup> in 2014 that US patient groups are gaining influence across “the entire drug development continuum” (Sellers, cited in Cavallo, 2014: no page). In an interview for the publication, Sellers cites the U.S. government’s ‘21st Century Cures’ initiative, which seeks to address the widening gap between the accelerating ‘science of cures’ and the often slow processes of drug regulation. As this work has demonstrated, gaining an understanding of the complexities of drug innovation, production, and regulation is a time-consuming research task for independent patient advocates, but one that it might be assumed to be best conducted independently to ensure an unbiased appreciation of the various stakeholders. Sellers’ view of far reaching patient influence is encouraging, but what happens to patient advocacy once it is legitimized and paid for by pharmaceutical companies? Are empowered patients further empowered by working with drugs companies for better access and attention to side-effects?

Pharmaceutical giants Eli Lilly & Co. have recently launched eMEET<sup>99</sup>, an online Medicine Evaluation Educational Training resource “to help patient advocates navigate the world of medicines development evaluation and assessment” (Taylor, 2014: no page). A multi-media

<sup>98</sup> Newspaper style publication (print and digital) of the American Society of Clinical Oncology.

<sup>99</sup> See O’Connor, Amy (2014) ‘eMEET: Bringing the Patient Voice to HTA’, for further information.

approach underpins modules on the following:

introduction and scene-setting - the true value of the patient voice; the journey of a medicine through the complex process of discovery, development and evaluation; an introduction to HTA [health technology approval]; HTA in practice, with an illustration of the complexities of assessment; and patient advocacy group participation in HTA - how to engage effectively to ensure that HTA panels understand patients' needs and preferences (Taylor, 2014: no page).

Developing digital resources of this nature allows the industry to adopt a significant role within patient networks. eMEET takes up a place in online support networks as a circulating industry-based narrative actively instructing patients about the processes of drug development and health technology assessment. Effective pressure on the latter might of course ease the flow of valuable drugs to market, potentially saving lives and sustaining an earlier return on industry investment.

The mutual benefit seems clear, but collaboration between relatively poor patient organisations and the wealthy pharmaceutical companies on who they depend for innovative (or indeed any) treatment for their disease is a contested area. Apart from their tendency to get sick and require drugs, patients, particularly when networked into groups, offer other forms of capital to the pharmaceutical industry. They can be used as active lobbyists of government/regulatory agencies for access to drugs, a rich source of feedback on the side effects of products, a ready source for disease-specific market research, and an effective PR

tool for demonstrating commitment to patient needs.

What may be viewed on the surface as a straightforward symbiotic relationship is of course massively skewed in terms of the economic power balance. In concluding that funding from and collaborative projects with pharmaceutical companies can aid the growth and influence of patient organisations, Herxheimer (2013) also acknowledges that such interventions have the potential to distort or even misrepresent the agendas of patient groups. Transparency then is vital, with relationships “fully acknowledged and open, without public relations flummery” (Herxheimer, 2003: 1210). There is a tangible sense across network debates that, despite the obvious power imbalance, there are advantages for both parties in the relationship. As such, it might be assumed that a stubborn adherence to the antagonistic binary between powerful neo-liberal corporate interests and potentially exploitable patients<sup>100</sup> belies the complex networks of associations both within and between the two groups, as well as what stands to be gained and lost in collaboration.

Herxheimer suggests replacing models in which VHOs (voluntary health organisations) are passive recipients of industry funding with those in which they retain independence while working collaboratively on practical or policy initiatives pertinent to those they advocate on behalf of. Herxheimer’s observation that effective collaborations are characterized by mutual gain and require that “each should make efforts to understand the internal culture of and

<sup>100</sup> For an interesting protest blog critique of the actions of the executive leaders of Pharmacyclics, see ‘Scientology Donor Bob Duggan’s Company Makes \$975 Million Deal With Johnson & Johnson/Janssen’ thread in ‘Media’ discussion on Whyweprotest.net. [Online] 2012.

external pressures on the other” (Herxheimer, 2003: 1210) are particularly pertinent to my own argument that circulating narratives of multiple enactments of CLL can make visible these internal cultures and external pressures for ‘other’ versions of the disease.

Despite the undeniable benefits of stripping back the connections that hold big pharma, regulatory processes, clinicians and their patients together through narrative and material intersections, there remains a residual tension in relationships between corporate pharma and independent patient advocates, voluntary groups, and charitable organisations. As with many power-imbalanced relationships, ‘transparency’ is the go-to byword for ensuring that abuses of power and influence don’t occur, but Batt (2014) challenges any notion that transparency alone can protect patients’ interests in the case of the pharmaceutical industry: “Research into the financial ties between drug companies and physicians, medical researchers and other actors in the system shows that transparency is not sufficient to ensure that patients’ interests will take precedence over those of the pharmaceutical industry” (Batt, 2014a).

Furthermore, Batt resists the common claim of pharmaceutical sponsored advocates (see Arie and Mahony, 2014; Batt 2014b) that patients *unequivocally* benefit from rapid, universal access to all licensed drugs:

Yet many new drugs are no better than those on the market and they may be less safe. They will inevitably be more expensive, which -- if the drugs are placed on formularies -- not only skews the spending priorities of universal health care systems to the detriment of patients but is rapidly making these systems unsustainable (Batt, *ibid*).

Uncritical acceptance of a mutually beneficial interest in the expedited approval and licensing of all new drugs might elide important implications for safety and funding. Previous sections in this chapter have demonstrated the growing strain on healthcare budgets represented by high tariff novel agents, and shown how in England, decisions made to approve new drugs by the CDF are always accompanied by decisions to stop funding others (whilst retaining the potential to keep drug prices high through a two tier system of approval). Fieldwork in my own study has observed rich network debate about how global health care providers will fund already expensive novel CLL agents, likely to become increasingly expensive as personalized oncology evolves. There is precious little network critique however of an ideology of *universal rapid* licensing and uptake that may ultimately serve to exacerbate broader fundamental issues of funding and access. As Batt (2014a) points out, pharma-funded patient advocates are generally adamant that their industry sponsors don't tell them what to say, as evidenced in her own research with industry-sponsored breast cancer patients. More chilling though is her assertion that "pharma funding buys silence on issues that groups speaking for patients *ought* [my emphasis] to bring to the table" (*ibid*), and the lack of open debate about the potential impacts of pharmaceutical industry sponsorship among the CLL patient communities I researched may represent an example of that silence.

'Bigger-picture' critiques aside, it is hard to argue that in the case of 'game-changing' (Rule, 2014) drugs such as ibrutinib, offering evidence-based hope to CLL patients, the potentially deleterious impact of avoidable bureaucratic delays in getting novel agents to market (Jonsson and Wilking, 2006) requires urgent attention. If patient groups are too poor and small in stature

to do this independently, then it might be argued they have little choice but to team up with pharma in order to be heard. Batt's own longitudinal research into the Canadian breast cancer movement from the early 1990s (when groups had no industry funding) to 2008 (when most breast cancer groups in the country accepted some industry funding) reveals some of the political contexts that have influenced the changing relationships between patient advocate groups and the industry. Over the two decades tracked by Batt, what she describes as increasingly 'neoliberal government policies' gradually depleted funding available to health sector groups engaged in advocacy, actively encouraging industry partnerships that the latter were all too happy to engage in. The outcome was "to split, and gradually change, the [advocacy] movement. Leaders critical of the pharmaceutical industry left in frustration while groups that refused industry money were marginalized, or died for want of funds." (Batt, 2014b: 132)

The question of how advocacy groups can secure adequate funding without undermining independent representation of the patient voice remains a vexed one. The networks provide the potential of patient empowerment in terms of knowledge and the ability to mobilise action, but the problem of independently funding activism remains. It seems that dissensus is successfully chipping away at traditional models of knowledge ownership in the clinical relationship. As narratives underpinning 'expert' knowledge intersect more freely with patient's own narratives in network spaces, many patients are becoming more empowered in managing their disease. Notions of ownership of expert knowledge are now highly contested, and clinical relationships are evolving to accommodate that. Patients too are learning about the political

economy of the pharmaceutical industry, the complexities of drug development, and the process of global regulatory mechanisms for new drugs. But the ownership of the resources to produce new drugs remains under the control of a small but powerful network of amount of global pharmaceutical and biotech companies.

However much patients know about the biomedical science and political economies of drug development, they remain dependent on corporate funding and profits to get the drugs they need. Unlike knowledge about one's body and disease, the means to develop and access drugs isn't accessible to all who seek it. Dissensus is perhaps less productive for patients desperate to access what the pharma companies have, and they need – in many cases urgently, although the underground US AIDS movement of the eighties provides an interesting case study of resistance to the powerful combinations of private-sector and state influence in the pharmaceutical industry. I want to focus briefly on that here as an example of the potential of patient networks to mobilize effective resistance even in a pre-digital era.

### **Dallas Buyers: A Model for Dissensus**

This section opens with reference to a film, and a book. In 2013, Jean-Marc Vallée's film *'Dallas Buyers Club'* was released to box-office success. Set in the mid-1980s AIDS 'epidemic', the film dramatizes the real-life story of Texan electrician Ron Woodroof (played by Matthew McConaughey). Woodroof was diagnosed with AIDS, and told that he couldn't access the drugs needed to keep him alive until they had undergone full FDA approval and trials. Under the



shadow of a thirty day prognosis, he launched a mission with a fellow AIDS patient to access and smuggle unapproved drugs into the U.S. for sale to other men destined to die before the drugs they need legitimately filter through into the medical establishment. Woodroof's venture represented a small node in a much bigger underground network of 'underground pharmacies' across the USA (New York and San Francisco particularly) sourcing unlicensed drugs in Mexico, Japan and elsewhere to smuggle back into the USA. In his (1992) book, *Acceptable Risks*, Jonathan Kwitny outlines the story of underground AIDS activists Martin Delaney and Jim Corti, and their attempts to research and access their own drugs, resist the hegemony of 'preferred' drugs such as AZT, set up their own 'trials', working with co-operative doctors, and generally subvert and circumvent mainstream regulatory processes in the face of an aggressive, lethal disease unbound by the rhythms of mainstream corporate drug development.

Both the book and the film show how ordinary men forced powerful politicians, pharmaceutical firms and doctors to critically examine the processes by and speed at which the US licenses medicines for dying people. Importantly, as popular cultural narratives they allow for consideration of the possibility of dissensus in relation to the hegemony of corporate pharma and its relationship with clinical and regulatory practices. This is particularly pertinent in relation to multi-faceted networked disease communities such as the online CLL community explored in this work. While I have seen little outright dissent in the CLL specific networks themselves, which are more strategically concerned with tracking and staying on top of the narratives of new drug developments and access that may save or prolong the lives of CLL patients, it is useful to remember that patients are hooked into much broader networks of

narrative exchange in their daily lives. In the cinema, or bookshop, they may be exposed to a range of equally influential narrative possibilities as they too intersect with the more localised networks they are embedded in.

As I have argued, the potential impact of networked sharing among patient communities extends across multiple facets of disease experience, and one of those is the clinical trial itself. Patients in the underground AIDS activist movement adopted a range of strategic practices of resistance such as navigating blinded clinical trials, and the sharing out of drugs on randomized trials with those on the placebo arm. Head of Clinical Innovation for Worldwide Research & Development at Pfizer in New York at the time of writing, Craig Lipset (2014) uses these as examples of how the scientific validity of the trials process can be undermined by networked patients even without access to contemporary technological communications. Once trials patients are socially connected on global social media, rather than confined to localized waiting room conversations of a pre-internet era, there is no telling what acts of (conscious or unconscious) challenge to trial protocol they might exhibit. For example 'coaching' each other how to successfully negotiate complicated eligibility criteria, and how (where not already obvious) to work out which trial arm they had been randomized to. Lipset also suggests that sharing experiences of side effects (so called 'safety events') might trigger similar anticipatory responses among fellow participants, affecting 'data integrity through a false spike in safety reports' (Lipset, 2014: no page).

In short, the potential for patients to mess with scientific method in trials contexts in a socially networked culture is considered significant by Lipset, who suggests that, whilst such information sharing can be positive, it also has the potential to “undermine the scientific integrity of medical research” (*ibid*).

My own study has coincided with increased trial activity in the CLL networks studies as the novel CLL agents described continue to roll out. Fieldwork reveals one of the dominant forms of traffic across support communities to be peer-to-peer debate on managing the side effects of drugs among trial participants (and those being treated with traditional CIT). Such exchanges are delivered in the spirit of mutual support and help among community members, rather than a desire to influence trials procedure, or to ‘plot’ or feed information on side effects back into trials data (another potential use of online information sharing in relation to trials which will be explored in the final section). However, networked exchange of personal treatment experience can be viewed variously depending on which versions of CLL they intersect with. Patients may feel mutually supported and reassured through peer sharing (although not necessarily of course) at the same time as trial organizers and sponsors may feel anxious about the potential for such exchanges to influence outcomes and findings. Lipset’s (2014) call for further research into the impact of participant peer-to-peer exchanges on the scientific integrity of the trial process, could be echoed by calls for further research exploring trial participant perceptions of control and empowerment through networked communication. It seems to me a naïve hope that increasing patient awareness of “the potential implications of social media use on the scientific integrity of the study in which they are participating” (*ibid*) or having clinical trial

sponsors and regulators “monitor social media use by trial participants to understand if conversations on the internet will affect their interpretation of study results” (*ibid*) will act to modify peer to peer sharing practices.

The varied motivations behind a desire to cure or manage a disease inevitably intersect, but are generally powered by entirely different drivers. The genie of trial participant peer to peer support will not go back into the medicine bottle in order to privilege the scientific research version of CLL over the vibrant web of versions of living with CLL exchanged in support communities every day. Trial design and expectation will need to evolve to accommodate the manner in which contemporary patients communicate, harnessing rather than attempting to control the rich seam of experiential trial data accumulating in informal online archives. That of course brings with it a whole new set of considerations surrounding the potential uses and abuses of aggregating individual patient data online, and the next, and final brief Translation and Perspective will look at these issues and bring the overview of network narratives and contexts surrounding treatment to a close.

## Translation: Data Sharing in Online Networks (PatientsLikeMe)

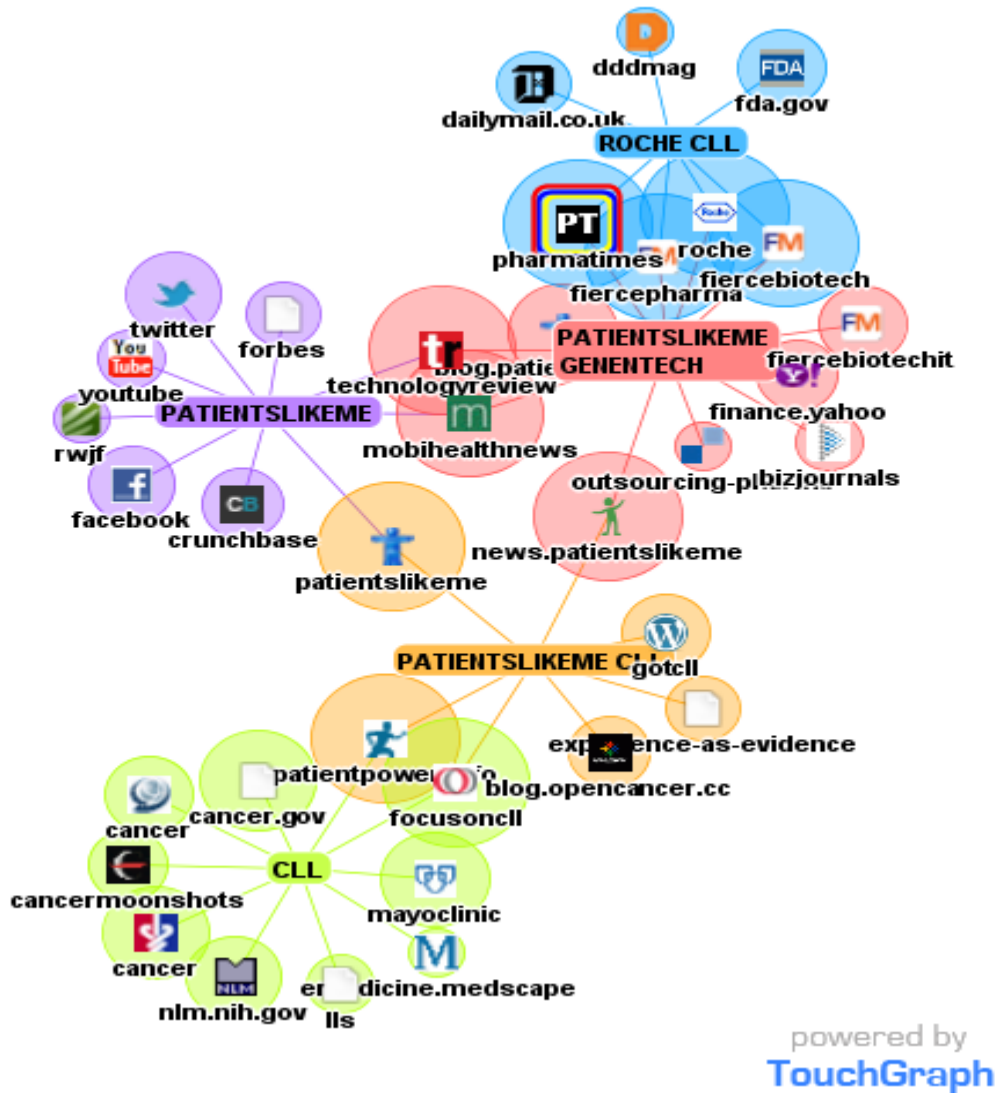


Figure 3913: TOUCHGRAPH (2015) network connections to PatientsLikeMe/CLL/Genentech/Roche [Network Map]. [Online] Available at: <http://www.touchgraph.com/seo/launch?q=patientslikeme%20cll>. [Accessed 26/07/2015].

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This Translation provides a very brief snapshot of the patient data-sharing health site, PatientsLikeMe as a case study of the ways in which technological entrepreneurs are harnessing the power of collaborative online data to make available, or sell to a range of interested parties. Personal online narratives are translated into mass aggregate data with, as the subsequent perspective shows, numerous uses potentially benefitting patients, scientists, and corporate interests alike.

Co-founded in 2004 by brothers, Benjamin and James Heywood and friend Jeff Cole in response to their experiences following brother and friend Stephen Heywood's diagnosis with ALS (Lou Gehrig's disease), PatientsLikeMe (PLM) is an internet application whose members volunteer detailed data about their disease experience in the spirit of peer sharing as a means of improving their outcomes. Individual patients receive their own graphic health profiles and aggregate data is collated into reports that can be accessed via the site, discussed within group forums, and individually through private messages. The site openly declares its 'for profit' status<sup>101</sup>, and informs users that it works with "trusted nonprofit, research and industry Partners who use this health data to improve products, services and care for patients" (site, 2015). At the time of writing, 407 members were listed on the site with CLL.

Logging in as a CLL patient, I can access an 'overview' page which gives me quantitative data about the CLL community on the site including the overall number of CLL patients, the amount

<sup>101</sup> Alongside the Omidayar Network (set up by e-bay founder Pierre Omidayar and his wife Pam), investment and advice for the platform was provided by e-commerce company CommerceNet, founded by Marty Tenenbaum, who also sits on the board.

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of new members joining that week, age at diagnosis and at first symptom, and gender.

Interestingly, at the time of writing the gender balance was 58% to 42% in favour of females, unrepresentative of the significantly higher incidence of CLL in males across the general population<sup>102</sup>, and perhaps indicating a greater willingness for female patients to share their CLL information in this way online that could sustain further research.

I am presented with a drop-down list from which I can click through to data on how CLL affects people, how people treat it, treatment comparisons, member journals, and new members. See Figure 39 (below) for a screenshot of the treatment comparison data to illustrate navigation and data visualization:

<sup>102</sup> According to Cancer Research, in 2011, there were 3,233 new cases of CLL in the UK (Table 1.1): 1,957 (61%) in males and 1,276 (39%) in females, giving a male: female ratio of around 15:10.1-4 The crude incidence rate shows that there are around 6 new CLL cases for every 100,000 males in the UK, and 4 for every 100,000 females (Cancer Research UK, 2011).

Image removed due to copyright restrictions

**Figure 40: PATIENTSLIKEME (2015) Screenshot of PLM treatment comparison page**

**<https://www.patientslikeme.com/conditions/186-cll-chronic-lymphocytic-leukemia/compare-treatments>  
[Accessed 10/03/15].**

I can also access data visualization on symptoms, symptom severities, methods and drugs used to alleviate them, a list of members experiencing these symptoms, and links to comments about these symptom specific experiences from CLL community members. Among the symptom data aggregated for CLL patients are insomnia, pain, fatigue and depressed mood. In addition, I can access aggregate patient reports on various CLL drug treatments, and access detailed information on CLL drug trials globally.

On joining the community, patients are encouraged to provide enough detailed individual data about their conditions to earn three 'stars' (rewarded with a free PLM t-shirt). This level of data, patients are told, will increase the power of their voice and 'accelerate real time research'.



## **Perspectives: Aggregate Data (Who Needs It?)**

In an attempt to evaluate patient peer use of personal health information on the Patientslikeme site, Frost and Massagli (2008) analyzed a sample of 123 relevant comments (about 2% of the total), noting a range of communicative behaviours building on highly disease specific commonalities. These include the ability to pinpoint other members with similar disease profiles, and thus foster and maintain useful online relationships with those most likely to have more to offer and gain from them. My own work has demonstrated that the heterogeneous nature of CLL can lead to mis-communication and frustration in generalized support community settings, the likelihood of which this more nuanced approach to online disease patient networking might potentially reduce. The authors conclude that explicitly sharing detailed health data within a community may be beneficial to patients “helping them engage in dialogues that may inform disease self-management” (Frost and Massagli, 2008: no page).

As this (and other) work has shown, networked data sharing surrounding a whole range of diseases occurs daily on an informal, unquantified basis on a significant scale. Some sites such as ACOR have their own resources for archiving threads and discussions into databases for members to research as necessary. This study alone, of a relatively rare blood cancer within a demographic of patients within which fifty is considered young, has revealed a vibrant community of online exchange of highly personalized disease details and experience (from genetic profiles to spiritual musings). The avowed aim of open sharing platforms is to provide a

locus for bringing together some of that global data into localized, computable nodes where it might be evaluated in order to improve treatment, care, and patient experience. In short, to take the everyday pulsing exchanges of ‘small disease data’ in peripheral online circulation and tap them into major arteries of open-source big disease data analytics that might make tangible differences to care and treatment protocols. If we consider that, according to Cloud Backup company Asigra, 90% of contemporary global data at 2014 had been created over just two years, and forecasts predict that by 2016 some three billion people will between them create around eight zettabytes of data online (cited in Hansen et al, 2014: no page), the potential for harnessing personal data for science and health is clear. Manovich’s (1998) work on database cultures indicates the broad cultural impact of the ways we store and circulate information in a digital era, and this move towards collaborative sharing of personal data as a kind of peer driven research methodology is a good example of such a cultural shift – away from the laboratory and organized small-scale project into global networks where individual narratives also function as data contributions.

Potential benefits of health-related Big Data have been identified in three key fields to date, those being disease prevention, the identification of manageable risk factors for disease, and encouraging changes in health behaviour<sup>103</sup> (Barrett et al, 2013). A tripartite approach can also be applied to categorizing big data flows in health informatics which Barrett et al broadly define

<sup>103</sup> These benefits are acknowledged in the design and implementation of knowledge seeking and data-motivated decision-making initiatives globally such as the Big Data to Knowledge (BD2K) and Infrastructure Plus Program set up by the National Institute for Health (NIH) in the US to provide a shared computational platform for the facilitation of large-scale biomedical data analysis for the NIH community (Barrett, 2013: no page)

as: 1) traditional medical data of the kind stored in patient records which have the potential to contribute to more effective approaches to the aetiology and treatment of disease in global health systems (this data potential to some extent underpins current campaigns to move towards electronic medical records); 2) large scale biomedical datasets such as genomics, microbiomics and other “omics”, knowledge of which might accelerate understanding and implementation of individualized treatment; and 3) social media and ‘quantified-self movement’ data providing an insight into how individuals and groups utilize digital platforms and technologies in health contexts.

As database culture offers new ways of thinking about archiving and sharing information digital pedagogies are also evolving. The concept of connectivism acknowledges the gaps left by traditional pedagogic theories in effectively accounting for learning in less formal, networked, technology-enabled environments. Pioneer, George Siemens has produced a list of principles to underpin the theory, four of which seem particularly pertinent to networked database knowledge exchange. Firstly is the principle that learning is essentially a process of “connecting specialized nodes or information sources” with the implication that anyone can enhance their own learning exponentially through connection with existing networks. Secondly, is the acknowledgement that learning may reside in non-human appliances: “Learning (in the sense that something is known, but not necessarily actuated) can rest in a community, a network, or a database” (Siemens, 2015), which appears to resonate with ANT’s perspectives on the

relationships and associations between human and non-human actors<sup>104</sup>. Thirdly, is the principle that knowing *where to find* information is more important than knowing information itself, and fourthly, that nurturing and maintaining connections is vital to facilitate learning, and provides significantly greater returns on investment than trying to understand a single concept (Siemens, 2015).

In a 2014 review of the literature and concepts in Big Data and science and healthcare, Hansen and colleagues (2014) conclude that Big Data and associated analytics are now of significant importance in harnessing the potential contribution of vast volumes of both formal and informal data in the field. This comes with a need to advance work in the fields of ethics, privacy, confidentiality and education surrounding the use of big data. Importantly, they acknowledge the need for further exploration of the contribution that the analysis of 'small-data' gleaned from social media, and the 'quantified self-movement' might make. But the uses and abuses of big data are a contested area in academia in which the fervour to read mass populations through an aggregation of personal health data is seen variously as panoptical, analogous with 19<sup>th</sup> century colonial approaches to the centralization of goods, knowledge, and power (Dourish and Mainwaring, 2012), commodification of the body on a grand scale, and just another form of biopolitical power mobilized into management of the self (Cheney-Lippold,

<sup>104</sup> See Bell (2010) who has worked on exploring the points of connection and departure between ANT and connectivism in his paper 'Network theories for technology-enabled learning and social change: Connectivism and Actor Network theory', published in the Proceedings of the 7th International Conference on Networked Learning 2010.

2011).

It is not difficult to see why powerful private sector and state institutions are keen to mobilize big health data into their knowledge and organizational infrastructures, but in their ethnographic study of the Quantified Self (QS) movement, Nafus and Sherman (2014) are equally interested in the forms of resistance demonstrated by individual data providers to the more potentially contentious uses of the information they provide.

Set up in 2007 by journalists Gary Wolf and Kevin Kelly of *Wired* magazine to explore the impact of personal tracking technologies on the lives of those using them, the QS movement now has over 20,000 members in thirty global locations, and is based on Wolf's premise that instead of using the common approach to data as a 'window' on people's activities, the movement instead employs the metaphor of a 'mirror' to evaluate "what kinds of reflection, learning, and personal insights might emerge" (Wolf, cited in Nafus and Sherman, 2014:1787). Nafus and Sherman's ethnography of QS members is primarily concerned with devices designed to be worn on or work with the body and to measure physiological functions such as REM and sleep patterns, heart rate, pace and cadence in exercise and so on. However, working with Cheney-Lippold's notion of the effects of individual use of such data monitoring devices as a form of 'soft biopolitics', they suggest that device users in the movement perform a kind of 'soft resistance' incorporating wildly idiosyncratic interpretations of the received wisdom behind the facts and figures underpinning benchmarks for achievement. A vast range of big data enthusiasts are drawn to the QS world in search of data supposedly indexical of optimal

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“health”, measured, recorded, and legitimized through medical discourse, but Nafus and Sherman point out that “QS practices simply do not cohere in this way” (*ibid*:1790).

My own study has demonstrated that some of the methods of data sharing that individual CLL patients use in the networks (listing labs, genetic profiles, and prior treatments after postings, using dedicated spreadsheets designed to record bloods and so on) are in some ways analogous to the translation of bodily functions and performance into quantifiable data that characterizes the QS movement. I have also demonstrated how equally idiosyncratic interpretation of the benchmarking behind these numbers and measurements can be in disease communities in terms of how people mobilize the objective nature of that knowledge into their personal narratives.

The degree of actual empowerment offered by such acts of individualized networked resistance is arguably limited of course once individual data is aggregated into broader networks state and private sector interests. In communities of serious disease, the body itself limits empowerment in terms of physical survival, although empowerment is a mutable concept in the face of life-threatening disease. As respondents in this study have shown, it can equally be applied to the power to live and die well with disease rather than solely how to cure or manage it medically. Data in the form of numbers read through the body in disease communities unarguably has different inferences though. Plummeting neutrophils and haemoglobin levels in a leukaemia patient for example have far greater implications than the indexical signs of disturbed sleep

patterns in the general population.

Data in that sense is 'harder' in communities populated by the seriously ill, although 'tracking devices' such as the Fitbit 'fitness band' which tracks activity and sleep patterns are finding a foothold in disease contexts. Drug manufacturers Biogen, global producer of a number of key MS drugs gave out free Fitbit devices to patients to monitor activity levels in return for their commitment to share data on PatientsLikeMe. MS disease progress can be measured in terms of reduced mobility, and Biogen are keen to harness the daily data readings that such devices can offer them to inform drug development (Chen, 2014).

The potential range of personal health device testing is vast. Diabetics already monitor their own glucose levels with personal devices of course, and have been doing so for many years, but San Diego Health monitoring startup Cue have recently launched a device that monitors the body at molecular levels, reading testosterone levels and diagnosing the influenza virus from a swab of bodily fluid (Winter, 2014). At the 2015 launch for their new smart-watch (with built in heart rate monitor), Apple also announced the launch of data sharing framework ResearchKit , a platform allowing medical researchers to create applications supporting enrolment of subjects into medical trials and allowing for the ongoing collection of research data.

The open-sourced platform builds on and can interact with Apple's existing personal monitoring framework HealthKit, and the product launch was supported by five sample apps built in collaboration with partner universities in US, UK and China and supporting research into

Parkinson's Disease, Cardiovascular Disease and Breast Cancer. Standardized real-time research data can be collected from research subjects using a software framework like HealthKit, with the potential to share data across multiple studies (Glance, 2015: no page). According to news reports, doctors in fourteen major US hospitals are currently piloting the service in trials to collate data and monitor patients remotely (Williams, 2015: no page).

Platforms such as Cancer Commons and PatientsLikeMe express an avowed aim to share scientific and experiential knowledge, to turn the mirror on data that might help speed up research, and improve treatment, even for patients approaching the later stages of their disease. There is some evidence that this is at least one of the outcomes, as demonstrated earlier in this section. Research is needed to evaluate how patients really feel about the potential uses of aggregate data, both positive and negative. Many patient responses to a PatientsLikeMe blog entry on openness and transparency written by co-founder Ben Heywood demonstrate a positive attitude to sharing their medical data (although this is likely to be a self-selecting audience, already engaged with the community), but the following respondent demonstrates some of the anxieties articulated more broadly about the hegemony of big pharma:

I have a thing against Pharma firms... they're in the business of keeping people SICK .. (otherwise, let's face it, they'd be so out of business) ... after all, pharmaceuticals are a huge lobby ... I don't know if I'm comfortable with my personal data/information being sold to these firms (Bilal Ahmed May 20th, 2010).



It seems reasonable to suggest that patients may share with the QS movement some concerns about the ultimate uses of aggregate data whilst still appreciating, benefiting, and even coming to rely on its more positive potentials. This is usefully articulated as dialogic dependence rather than outright defiance, where “QS politics are not defiant toward the dominance of big data—they are instead in dialogue with it and reliant on it” (Nafus and Sherman, 2014: 1793). I would suggest that this view is to some extent relevant to an exploration of the relationship between disease communities and big data, albeit that the stakes are significantly higher for most cancer patients, and the concept of ‘choice’ significantly restricted. Despite the acts of resistance, individual interpretation, and stories of success in sourcing, and accessing life-changing treatments, there is also the inevitable conclusion that users remain subject to the broader biopolitical reliance of late capitalism on individualism as a driver of the production and consumption of healthcare technologies.

The sponsorship of Cancer Commons by Pfizer, and the announcement from PatientsLikeMe in April 2014 that they had, for an undisclosed sum, agreed to grant access to five years’ worth of all de-identified patient data on the site to Genentech, a division of Roche (Comstock, 2014: no page), perhaps serve to exemplify that point, while remaining wholly uncontroversial in terms of the mission statements for the platforms concerned. As PLM openly state on their site:

We create partnerships between you, our patients, and the companies that are developing products to help you. To do that, we take the information you entrust to us and sell it to the companies that can use that data to improve or understand products or the disease market (PatientsLikeMe Help Centre, 2014).

This entire study has focused on everyday data sharing in CLL networks through its exploration of circulating and intersecting narratives therein. Often informal and serendipitous, buzzing between varied nodes of institutional, professional and independent interests, a cacophony of CLL data resonates daily, and I have attempted to trace the more vibrant, sustainable, and dynamic actors keeping the nodal connections alive. This section has demonstrated some of the contemporary approaches and attitudes to formalizing and capitalizing on that data through medical informatics, an industry in its infancy. My sense (as both researcher and networked patient) is that there will always remain a vibrant 'underground' web of disease communication, but harnessing of individual data for aggregate evaluation is a growing market and an integral part of any overview of disease communication networks online.

## **Chapter Summary**

Biomedical and pharmacological innovations are undoubtedly transforming the world of cancer treatment. CLL has become a key player in those innovations. A genetically heterogeneous, relatively slow moving cancer offering huge potential for research and experimentation in drug development, it has rocketed from relegation to an almost 'orphan' disease in terms of interest and input, to a modern oncological media star, improving treatment experience and outcomes for many CLL patients, and significantly increasing the stock of the major pharma and biotech companies investing in it.

This chapter has traced clinical perspectives on changing treatment protocols, highlighting both the personal and political affiliations clinicians may have with particular approaches, and the very real challenges that face the clinical community in evaluating how best to incorporate novel agents into changing treatment protocols. I have shown how these clinical versions of CLL treatment intersect with patient experience in online networks potentially enabling patients to understand the broader contexts within which their experiences in discussing treatment with their own doctors are positioned.

Aside from the challenges to clinicians and those involved in drug development posed by the heterogeneous and mutable genetic nature of the disease itself, this chapter has shown a major issue in the networks to be that of cost. Networked CLL patients are made very aware of the implications that the cost of new drugs such as ibrutinib<sup>105</sup> can have on issues of access and sustainability for these treatments, and the chapter has traced a number of associated narratives across key nodes addressing the political economy of the pharmaceutical industry and its role in setting drug tariffs. David Shaywitz's (2013) feature on ibrutinib's convoluted evolution from concept to drug across academic labs, minor biotech companies to pharma giants illustrates the fragile and complex journey an ultimately successful drug might make to market. Fieldwork shows that this story provoked minimal member responses among CLL patients in the key nodes, but that it found its way in to them, and provoked some response demonstrates how, through the efforts of dynamic actors, disease communities are potentially

<sup>105</sup> On FDA approval in 2013, Imbruvica (ibrutinib) was given a tariff of over \$90 per pill by Johnson & Johnson/Pharmacyclics. A standard dose of four pills per day works out in the region of \$130,000 per year – one of the highest prices ever for a cancer drug in recent memory (Staton, 2013).

exposed to a sophisticated understanding of the institutions and practices behind treatment decisions made on their behalf (or in collaboration with them).

As with the study as a whole, the circulating narratives come in many forms - from medical research papers to personal testaments, but perhaps more evident here in the circulating narratives of treatment specifically than the other themes in this has been the role of the news media itself in disseminating information. Stories have circulated across key nodes from mainstream news reports of the successes of new leukaemia treatments, through in depth features on particular drugs, to professional and business-to-business publications in the clinical, pharmaceutical, biotech, medical informatics, and business press.

This chapter has traced several of those, and drawn on others both to inform perspectives and to demonstrate how they are circulated and responded to by networked CLL community members. A high degree of scepticism, resistance, and even anger in response to inaccurate and sensationalist mainstream reporting and its potential impact on public knowledge of what it means to live with CLL has been observed in this project. This aligns with contemporary perspectives on problems with mainstream media representations of health and science whereby some journalists can be seen to take a cavalier attitude to reporting and fully understanding the evidence they draw on. As this thesis shows, changing cultures of news production and consumption among more informed audiences make it more likely that journalists will be called to account for their errors in a world where “ Anyone can write, and publish online, and appear in Google news alerts: the NHS, medical research charities,

individual academics, journals' press offices" (Goldacre, 2009). Conversely, some networked patients have been observed to utilise pharma press releases in the business news as a means of keeping up to date with treatment evolution, demonstrating how disease communities can demonstrate sophisticated intertextual skills in developing a multi-versioned attitude to knowing their disease.

Access to the new drugs is unsurprisingly a key theme in the networks, and therefore in this chapter, which has explored network narratives highlighting the relationships between the pharma industry and the regulatory bodies that control the licensing of their products. This is an area of disease practice attracting a high degree of patient involvement in the CLL networks observed. The Perspective sections show varying theoretical attitudes from critiques of an ideology of rapid access for all new drugs with its potentially negative implications in terms of safety and future economic sustainability (Pharmaphorum, 2014; Skipla-Serry, 2013), to Johnsson and Wilking's (2006) bold assertions that some patients are dying as a result of inequities in global regulatory timelines and funding policies for new drugs. The Translation focus on Chaya Venkat's unsuccessful advocacy attempts to work with pharma companies to secure compassionate access for ibrutinib early in 2014 immediately prior to its licensing shows the very human cost of being unable to access drugs outside of trials, for which patients might not be eligible or geographically close enough to apply for.

Access to and participation in trials was a dominant theme among patient narratives surrounding treatment, again related to access to novel agents. Once again, network

observations shows the playing field to be less than level in terms of trial availability, eligibility, and the amount of information and encouragement patients are given by their clinicians in relation to considering trials as part of their treatment decisions. Perspectives uncover a number of obstacles to trial engagement ranging from time pressures in the clinical setting among clinicians not directly involved in trial delivery and recruitment to poor medical literacy, inadequate understanding of the trials process, and a lack of confidence among patients to ask about or get involved in trials.

The increasingly accepted success of novel agents is producing high accrual rates in trials for novel CLL agents however, and translations showed how key CLL clinicians and networked patients are working together in many cases to increase trial knowledge among the CLL patient community and strive for direct advocacy in relation to early access for these drugs.

Finally, the chapter has focused on the emergence of new forms of data sharing and management across networked disease communities, looking at the rise of collaborative e-science communities such as PatientsLikeMe, and their potential contribution to more effective and expedited research and treatment developed as an era of personalized medicine dawns. The work shows some interest across the CLL network in this kind of platform through disease specific membership on the site, and demonstrates how aggregate data is visualized and presented. Perspectives in this context focus on cultural aspects and attitudes of networked individuals sharing big disease data in relation to its biopolitical implications as individual experience is translated into aggregate data and mobilized into the political economies of

powerful public and private sector institutions.

It seems that many patients are happy to enter into a more open-source data sharing environment, in which they trade privacy and ownership of their personal disease data for the greater common, and of course personal, good that may come of it. Although some unease is articulated surrounding pharma company access to their information, the general feeling seems to be that this system can only improve the restrictive and somewhat homogenized systems of patient feedback employed in current drug development approaches, and possibly lead to improved treatments and access to them. For people living with life-changing and threatening diseases such as CLL it seems, everyday community exchange tends to focus on the immediate and material concerns of staying alive, whatever the broader political implications of that might be. As this chapter has shown though, when those political implications impinge directly on the business of staying alive, for example in the setting of drug tariffs, policies surrounding funding, and regulatory processes impacting on access to drugs, then key actors in the community will become politicized in their narrative sharing practices in order to mobilize wider responses among the community.

One of the major themes of this entire chapter has been one of perceived inequity in access to treatments. It is clear that the current binary tradition of watching until waiting for treatment that, in itself, is a risky prospect, may soon be superseded by the potential of new prognostic and pharmacological technologies to create more nuanced, individually tailored, and safer treatment protocols. For all of us living with CLL now this is undoubtedly good news. It brings

with it though a good deal of frustration for those needing treatment at the cusp between traditional approaches to care and emergent brave new protocols as my own experience, and network responses to it set out as a Translation in this chapter demonstrates.

One (Cornish) IOB respondent makes the point that even thinking about potential drug regimes has limited value given that the choice of treatment is ultimately limited to what is available locally/nationally:

*My consultant has told me that I will probably need chemo drugs this year. I have avoided researching drugs, because I can only have what is available. Unless I take part in new drug trials, which again only depends on stage of disease and availability (IOB Survey Respondent 2).*

Despite all of the sophisticated narratives circulating online in relation to various institutional, professional and personal enactments of CLL treatment, and the many success stories of access to new treatments with good outcomes to date, this respondent makes a pertinent point. She, and many others of us like her, represents the gap between aspirational global CLL research and the information that circulates about it on the web, and what patients located at regional, non-specialist points of delivery might actually have available to them. As new protocols replace old in increasingly personalized treatment approaches, it is likely that even more patients across a range of cancers will find themselves in the real-time void between past and future treatments, where some will inevitably have to rely on traditional treatments and others will move forward to new paradigms. Networked patients put themselves in the best position



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to gain access to new drugs, but as the above respondent shows, that knowledge and understanding of drug developments doesn't necessarily translate to access.

Further research is needed to evaluate both the psychological and survival implications of these inequalities for increasingly informed patients who are now much more likely to know what they might be missing. Even more important perhaps is further research into treatment outcomes for those patients outside of support networks who *don't* know what they're missing unless their doctors tell them.

## Chapter 6: Thesis Summary

*“My initial experience of illness was as a series of disconnected shocks, and my first instinct was to try to bring it under control by turning it into a narrative” (Anatole Broyard, 1993:308).*

*On-line narratives are not just changing our concept of authorship; this new kind of narrative also refuses to fit the usual concept of genre. Electronic illness narratives are an amalgam of literary and nonliterary forms, including autobiography or biography, journal, and medical chart” (McLellan, 1997: pp100-101).*

### Translation: A Diagnostic Tale

It's a cold and cheerless afternoon in late February ... one of those occasions where incipient damp and gloom conspire to reduce the horizons and possibilities of a day. My tutorials are done, and I am frantically trying to extricate myself from the endless undone tasks for the day before leaving campus for an appointment with my GP. He has results for me from a recent blood test. I am tired ... bone tired and feverish ... have been for weeks now. I just make the 4 o' clock bus into town and collapse into my seat amongst the buoyant chatter and canned music of homeward-bound students. I think about my lecture tomorrow, and the prep I will

need to do this evening. I want to sleep. At the surgery I find another seat to sink into whilst I wait to be called. Kids play noisily with the pile of broken plastic toys in the corner of the room. The incessant clatter is irritating, but I am reminded with some nostalgia of the days when my own (now teenage) boys would do the same. It seems like yesterday. I flick through a celebrity magazine: tales of weight gain and loss, fashion successes and failures, the scandals, trials and tribulations of celebrity love.

The room smells of damp clothes – it is raining outside. A number of people sit with me on the plastic chairs waiting to swap symptoms for a diagnosis. I wonder what's wrong with each of them as I look around me, surveying them covertly for clues. I suppose that they do the same with me. The previous patient exits the consulting room, and I guess I must be next. The GP follows him out, avoiding eye contact with anyone in the waiting area, and goes into an ante-room where he talks to a nurse in hushed tones before returning to his room with a sheaf of print-outs in his hand. I think nothing of it, and continue reading the magazine. I take a professional interest in the cultural obsession with celebrity and am absorbed. He calls me in, sits me down, smiles oddly at me and then says (as if reading instructions to himself) "OK, let's do this properly – would you mind getting up on the couch please so I can examine you". I am slightly surprised, but do as I am bid. He feels my abdomen, sits me up and feels in my neck.

In hindsight, I know what he was looking for – the swollen liver (hepatomegaly), spleen (splenomegaly), and lymph nodes (lymphadenopathy) that signify the accumulation of rapidly

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proliferating immature and malignant white blood cells in the factories and storehouses of the immune systems of leukaemics.

I am back in the chair. He looks at me again and tells me that all of the tests run on my blood were “absolutely fine.” He pauses ... “except your white count.”

I look at him expectantly, awaiting numbers, explanations, maybe a prescription or an edict to rest at home for a couple of weeks? He says nothing.

I shatter the heavy silence. “How high?” ... I ask.

“Sky high” he replies “67k” (a “normal” wbc would be in the range of 2-5k, but I can’t remember the normal counts at the time).

I quickly dredge the silted depths of my medical knowledge - I gave up nursing over 20 years ago to start my academic career. It must be an infection obviously ... I hazard my guess.

“No” he tells me. “It’s not an infection.”

I am momentarily stupefied (in hindsight it seems so obvious – what was coming).

“You were a nurse weren’t you?” he asks.

Then – sliding the lab report across his desk to me, he points at the words “frequent smudge cells - probable CLL” printed in the section reserved for the pathologist’s comments. He won’t say it – and I genuinely don’t recognize the acronym. I was an emergency nurse. Haematology was not my specialism. I shake my head.

“Sorry” I tell him “I don’t recognize it”.

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I am aware of feeling annoyed with myself. I have failed the test he has given me, disappointed him somehow, and now he is going to have to *tell* me the answer. He looks nervous.

Reluctantly he translates the acronym for me.

He tells me I have chronic lymphocytic.

**LEUKAEMIA**

My ears immediately ...

... shut out every sound in the room

other than his voice as I hear it

telling me ...

...as if through noise reducing headphones...

...that it is

***IN - CURABLE***

(though apparently treatable)

He tells me he doesn't know very much about the disease, that he has no real idea of the prognosis...

**(...*maybe five - 5 - years, maybe more, maybe less...*)**

...that bizarrely it does not fall into the “*emergency*” category of the NHS referral algorithm and that I may have to ... wait “some time”... to see a consultant specialist.

When I try to push him for information (I don't really know yet what information I *need*, but I am wondering already things along the lines of ... what will my life look like now? How should I envision my future? How long will I stay in the world? Will it hurt? Will my hair fall out? What drugs will I have to take? Will I have to stay in a hospital..?) he tells me that I should:

**“look it up on the internet”**

And here he hands me the sheaf of papers I saw him pick up from the printer earlier – a summary of the disease for the newly diagnosed from an online CLL support group.

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Finally he tells me that he is “very sorry”. I believe him, although I sense that he wants me to go away now. I leave the surgery in a state of profound shock.

As I walk the short and familiar route home through the drizzly dusk, my perceptions of myself ...of time ...and of the way that I inhabit the world ...begin a process of profound change.

Everything around me looks the same, but the mundane reassurance of local topography taken for granted for so long has gone. What is this disease that has altered my blood, that has weakened my immune system, that has swollen my lymph glands, that can't be cured, that in all probability will end my life much sooner than I had expected to die, and that now defines *me* as a cancer patient?

I need new maps. I take my doctor's orders: I look it up on the internet, but *it* turns out to be many different stories which I, like others diagnosed with cancer, must now learn to navigate and accommodate...

## **Perspectives: Thesis Summary (A Return to Aims)**

I think it useful here to return to the aims set out at the start of this work as a means of signposting this summary of my work:

- To explore and map the evolution of patient illness narratives as they move into circulation with a range of other narrative enactments of disease online.
- To locate and map the networks within which multiple CLL narrative enactments circulate and intersect online, identifying key nodes and actors.
- To make visible the key themes and issues faced by those living with CLL through mapping narrative themes online.
- To reveal the major points of intersection of the various narrative enactments identified, highlighting synergies, tensions and obstacles in the bringing together of multiple enactments of CLL online.
- To utilize and adapt object-oriented methodologies for mapping online narrative networks and flow.
- To design a methodological approach for writing up multiple narrative enactments in a way that prefigures the ontological politics of the project.

For clarity, I will address each aim in turn in the following sub-sections:



## **Evolving Illness Narratives: Re-territorializing through Digital Assemblage?**

In part, this work has been about studying an evolving form of illness narratives in digital contexts. Frank's (1997) notions of bodies and voices quite literally silenced by illness *and* its treatment, and responding through the narrative approaches of chaos, restitution and quest is a starting point for any work on illness narratives. Frank's work is focused on print forms however (now including graphic novels), and digital contexts produce different practices and possibilities:

But in on-line, ongoing, collaboratively constructed narrative, the inner workings of the process--reconsiderations, retrenchments, and reaffirmations--are much more transparent than in a finished print work. Where the electronic narrative stands relative to the unfolding of the story is thus often in flux (McLellan, 1997:101).

In this work, I have asked whether the way that many CLL patients online recontextualize a range of alternative texts into their own stories, including medical and scientific discourse, might be read as a means of re-claiming voices (and ultimately bodies) from the threat (actual or realized) of silencing - not simply by narrativizing in *resistance* to medical and a range of alternative authorities but by attempting to understand different enactments of disease, *incorporating* them, and engaging with them as an integral part of our stories?

Recontextualizing clinical research aimed at other clinicians and professionals; research papers written for a scientific community; pharmaceutical press releases written for clinical and business contexts; shared patient stories; lab reports written for doctors; and policy papers

inflected towards a range of civic and institutional contexts into everyday and ongoing personal illness narratives online has the potential to 're-centre' more powerful (and potentially silencing) discourses within patients own stories. As Bauman and Briggs (1990: 74) note in their work on agency in digital storytelling:

“decontextualization from one social context involves recontextualization in another...[it is interesting to consider]... what the recontextualized text brings with it from its earlier context(s) and what emergent form, function and meaning it is given as it is recentered ...” (Bauman and Briggs, cited in Hull, no date:33).

This reflects the narrative *translation* processes made visible by this work, in which I have shown how various elements of what we understand as CLL survive, but evolve as they move across multiple narrative versions online in a constant process of 're-centering'. This is better described for the purposes of this work as a process of re-territorialization, given the multiplicity and constant kinesis of 'centres' mapped.

As Mette Hoybe and colleagues (2005) conclude, narrative action through story-telling in health support forums can be an empowering process, giving patients resources to move from the submissive and isolating effects of a cancer diagnosis to active participation in new social contexts. The recognition of the experience offered by the presence of such communities opens up opportunities for sharing information and experiences about disease that are at once collaborative and social yet also have the power to underpin individual approaches to learning to live with cancer. Hoybe and colleagues define 'empowerment' in the context of their research as that which comes about not just through obtaining information, but also, and

importantly, through the personal strength gained from social support in the network.

Empowerment occurs in this model through the shift from 'being *acted upon* to be *acting* in intersubjective storytelling' (Hoybe et al., 2005:217). The intersubjective storytelling of internet support groups has therapeutic potential where effective story telling can "influence the subsequent actions of the teller and the audience" (Mattingly and Garro, 2000, cited in Hoybe et al., 2005:217).

At the level of everyday narrative exchange in the CLL communities, clear material effects are observable as a result of writing, reading and sharing these narratives made manifest in patients changing medical teams, accessing trials, learning patterns of disease management through others' stories and so on. All of this clearly has a material effect on the lives of some people living with CLL, and also has the potential to feed back into clinical approaches through the sharing of narratives between patients and their doctors. The roles of narrative distribution in extending the scope of this information economy are varied. Kathleen Pontius highlights one of the potential transformative impacts of networked narrative distribution in her work on young adult cancer patients and cancer narratives:

Challenges to the existing dominant cancer narrative and the creation of a fully formed constitutive rhetoric are still in their formative stages, but the initial development of alternative cancer narratives are starting to expand the definitions of what cancer is "supposed" to look like and how it "should" be experienced" (Pontius, 2008:99).

Working out how to 'do' CLL is a common aim amongst the narratives of CLL patients online, and by this I mean more than just understanding how the disease works and what we should be

doing and asking our clinicians to do in terms of managing its clinical course. As Evans and colleagues have shown, the issues of liminality faced by CLL patients can make it even more difficult to inhabit a suitable narrative in the face of the somewhat limited cancer narratives in cultural circulation to date. As Pontius points out above, the production of 'alternative' narratives are slowly beginning to challenge limited and singular perspectives. The assimilation of multiple circulating texts or objects of CLL into individual and group narratives has the potential to open up a new world of pathography that could radically expand views of how cancer "should" be experienced by a range of actors involved in enacting it, and not just patients.

The utopian implications of this need to be tempered to some extent by the knowledge that the resources required to mobilize online support, and to contribute effectively to online debate, are not universally accessible. Furthermore, as observed in this project, the majority of online health community users are lurkers rather than active posters, who make up a small percentage of community members. In reality then, a relatively small amount of key actors will be producing the heteroglossic effects of community interaction in the networks, and the subsequent learning, support, and ongoing narrative reconstruction opportunities produced by the discussion is not equally distributed across or necessarily representative of the majority of community members who consume it. It is also the case that individual perspectives of key network actors can at times dominate communities or particular debates as acknowledged by the following respondent describing her site preferences:

*CLL topics was a great help to me around the time of diagnosis. I kept just to this site, in particular I valued someone putting the research studies into "layman" terms. I do miss this site, and although Health Unlocked is informative I have found that it is dominated by a few people with strong views (IOB Survey Respondent 195).*

The work has shown that not all patients find sharing their stories in online communities to be therapeutic or empowering. Some are strategic in their avoidance of online information and of other people's stories which have been described by some respondents as 'self-obsessed', overly negative, or productive of dominant perspectives. Others have claimed to use online sites purely for information with no wish to engage socially with other CLL patients. However, the majority of respondents have been overwhelmingly positive about the benefits of sharing stories and advice online, and online narrative exchange does seem to have the potential to at least provide the resources for community members, active or lurking, to begin to make sense of life after diagnosis with a disease which is defined by uncertainty. It would seem that digital pathography is an evolving illness narrative form with much potential to expand our understanding of disease experience in a culture that is at once informational and narrative, technological and grounded in the subjective experience of illness.

### **Patient-Centredness in a Connected Information Economy**

One of the key points of this work has been the impact of information and knowledge gained online on clinical relationships. Tom Ferguson's view of the 'e-patient' as an informed, engaged, equal partner in their own medical treatment (2007) informs my approach, but clinical

relationships are (at least) a two-way process, and whilst an evolution in clinical attitudes is underway, this work has shown it still has a way to go. This manifests in a degree of inequality across the CLL patients studied, with some able to collaborate with and contribute to treatment decisions where they wished to, and others meeting with frank resistance, or at times derision from their doctors.

In his work on the 'grey zone' (ambiguity) of health and illness in society, Alan Blum disavows the model of professional excellence as one-way flow of technical proficiency from (knowledgeable) specialists to (ignorant) non-specialists. Instead, he imagines an 'intervention' in which the non-specialist is "engaged or moved to develop a stronger relation both to the specialty and to its subject matter, perhaps by taking initiative for influencing its redefinition in some sense" (Blum, 2011:98). Such interventions are consistently evident in online support networks, as patients engage with, gain expertise in, and become advocates for different models of care for CLL. Tensions persist though in a culture where medical expertise and specialism traditionally revolve around an axis of highly informed doctors telling poorly or un-informed patients (and other non-doctors) how things work. Put more plainly, "The excellent doctor must be a specialist who cannot on his own ground risk putting his excellence into question because no other than he and his circle seem qualified for such an engagement" (*ibid*), and neither party engages thoughtfully with the other in a model where "the specialist can be expected to have no respect for the ignorant, and the ignorant can only sulk resentfully at her exclusion" (*ibid*: 100).

Adopting ‘patient-centred’<sup>106</sup> practice has been one approach to acknowledging the fact that both patient and clinician have their own areas of ‘expertise’ that together can produce synergistic models of care (Bleakley, 2014). Traditionally, the distinct areas of ‘expertise’ recognized in this model bifurcate along a phenomenological patient/rational clinician split in which patient knowledge of their socially situated illness experience, attitudes to risk, and values/preferences is matched in a binary model by to the expertise of the clinician in diagnosis, aetiology, prognosis, treatment options, and outcome possibilities:

In shared decision-making the patient’s knowledge and preferences are taken into account, alongside the clinician’s expertise, and the decisions they reach in agreement with each other are informed by research evidence on effective treatment, care or support strategies (Coulter, and Collins, 2011:3).

In other words, the knowledge-based expertise of the doctor remains stable and unchallenged by the experiential expertise of the patient. As addressed in the introduction, narrative itself is evolving to adapt to the informational and digital moment, and it seems clear that so must those relationships traditionally based on one party or group holding *all* the knowledge cards in a given category (as demonstrated in patient responses used so far in this work). In an information era, fixed dualistic distinctions dividing patients and clinicians in this way appear anachronistic and naïve as patients become more informed about treatment options and prognosis, and clinicians more keyed into socio-cultural attitudes to health and medicine. Ian

<sup>106</sup> According to Mike Farrar, chair of the Royal College of General Practitioners’ ‘An inquiry into patient centred care in the 21st century’, patient-centredness describes “a new type of health system where empowered citizens are able to identify and manage health risk factors, receive individualized and holistic care, and are demonstrably equal partners in managing their health” (Farrar, 2014:3).

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Kennedy (2003 Chair of the Healthcare Commission) describes a mature culture in the NHS as one that will settle on:

...sharing power and responsibility, on a subtle negotiation between professional and patient as to what each wants and what each can deliver... The currency of this exchange is information. The mature culture will recognise the value of information within a patient-centred system (Kennedy, cited in Hardy, 2004).

The type of information each party is expected to contribute to a 'patient-centred' economy can no longer be hermetically boundaried though, and putting those patients actively involved in seeking information and support for their illness online at the 'centre' of clinical relationships requires acknowledging that they are already meshed into information networks outside of the clinical relationship. Put more simply, the aim may be to put every patient at the centre of the clinical relationship in policy terms<sup>107</sup>, but the clinical relationship may not be at the centre of every patient's information and support seeking practices. Patient *connectedness* may better describe this emerging phenomenon, and should be taken into consideration when interpreting policy statements such as the following from Mike Farrar, Chair of the Royal College of General Practitioners 2014 Independent Inquiry into Patient-Centredness in the 21<sup>st</sup> Century:

Critically, however, patient centred care also means that the varying needs, capabilities and preferences of individual patients and their carers must be met on an individual basis. For example, some want more involvement in their care, some are happy with a

<sup>107</sup> See the Royal College of General Practitioners' 'An inquiry into patient centred care in the 21st century', published in November 2014 by the Royal College of General Practitioners. <http://www.rcgp.org.uk/policy/rcgp-policy-areas/~media/Files/Policy/A-Z-policy/RCGP-Inquiry-into-Patient-Centred-Care-in-the-21st-Century.ashx>



strong professional lead; some are very capable of drawing on new technologies, some less (RCGP [Farrar] 2014: 3).

Differences in desire and capability among patients to draw on new technologies to increase their contribution to treatment and care decisions have certainly been evidenced in this work, with a very small minority preferring to leave everything to their doctors, and others struggling to overcome medical literacy problems. A significant majority (79%) of the 222 patients responding to the question of whether they discussed what they learned online with their doctors, said that they did. Not all of them reported positive clinical responses from their efforts however, begging the question of how far and how soon an internalized system of professional medical expertise whose exclusivity is largely dependent on lay ignorance of the technical aspects of anatomy, physiology and biochemistry will be willing to flex to accommodate a new breed of increasingly medically literate patients benefitting from the democratization of knowledge on the internet. This is not necessarily driven by a patient desire to challenge professional expertise. In the case of diagnosis with a rare disease, or one with less available disease-specific specialists such as CLL, a turn to online auto-didacticism and support seeking may seem to be more of a necessity for patients wishing to access the highest or, as this work demonstrates, even just acceptable standards of care. The consequent accrual of expert knowledge that many patients in this position demonstrate requires some sophisticated negotiation between them and their doctors if it is to transfer to an empowered relationship, rather than one that is ultimately frustrating or potentially threatening for both parties.

## **Identifying the Networks**

This thesis embodies four years of fieldwork, including the largest scale survey conducted to date of CLL patients online. Attitudes to their disease and their online practices have provided a sound overview of the major nodes, actors, and networks among a predominately UK and North American cohort. The network shape would change were I to have included European sites, but this work was confined to English speaking network nodes for ease of assimilation. The CLL Online chapter particularly outlines the major nodes, and lays bare many of the practices of online use employed by the CLL patients who responded. The In Our Blood survey online as a source of much of that data has operated as a network node in its own right, making heard a number of voices that have been silent in the networks for a number of reasons. The work has incorporated as many of the key nodes and actors mentioned by respondents as Translations for closer exploration, visually mapping their links into broader networks using TouchGraph software where possible.

Over the course of the research, some nodes have become less active than they were at the start (Macmillan CLL Group), others have grown significantly (CLLSA Health Unlocked), and two major nodes have become dormant due to retirement (Chaya Venkat's CLL Topics), and death (Terry Hamblin's Mutations of Mortality blog). A number of individuals have been identified as major actors in the networks studied, most of who appear in the Translation sections. Their actions and energies, alongside the software and hardware of multimedia platforms and global communications technologies mediating and translating CLL information across boundaries, are

largely responsible for keeping the multiple narratives explored here flowing and intersecting with each other. These actors effectively choreograph the network effects observed in this work, and usually do this for little or no financial return. CLL narratives do not flow effortlessly around the networks. They have to be selected, put into circulation, contextualized and often literally translated for lay audiences. Capable individuals may source multiple narratives for themselves, and what motivates and equips some people to put them into circulation with others, and even form vibrant network nodes themselves is beyond the scope of this research. I am flagging this up for future exploration however as it is central to an understanding of how successful network effects in cancer support might be replicated elsewhere.

### **CLL Online: Key Issues**

Aside from tracing the processes and effects of network activity surrounding CLL online, it was one of my aims in this work to make visible the key issues emerging for those living and working with CLL through an exploration of the narrative circulation. This 'political imperative for visibility' (Bassett and O'Riordan, 2002: 243) draws on my own experiences of CLL as an under-represented, and misunderstood disease, the consequences of which I, and thousands of others, live with daily. This was a challenging element of the research, having to balance an ethical responsibility to my respondents, and the stability of my own place as an active member in the support networks, with the sense that there was much going on in these unseen, private hubs of narrative exchange that could expand understanding of what it means to live with CLL,

and of methodological approaches to studying disease online generally.

Working closely with fellow CLL actors online to set up my work, and reflecting on my methodological approach as I proceeded enabled me to position myself in a way that was ultimately neither threatening to them or myself. In that sense, I am indebted to those everyday network actors who took the time to get into dialogue with me about this when I launched the project in the community. The addition of the survey as a network node in its own right was fundamental to that process, producing 10,000 words of narrative account from 267 CLL patients, along with the observations made by spending time in the networks every day over a four year period. I have had plenty of opportunity then to identify what concerns those of us living with CLL.

The work has presented these key issues in three sections under the headings Diagnosis, Prognosis, and Treatment. This is not groundbreaking, nor CLL specific, as it might be expected that anyone's disease experiences could be categorized in this way. In reality, there is a good deal of crossover between these categories, and it is in mining down into the minutiae of daily narrative exchanges that the CLL specific issues can be identified. Each chapter has dealt with these in fine-grained detailed, summing up observations in extensive 'summaries', noting here that 'conclusions' work against the grain of an ANT approach that claims close, detailed, even baroque description without necessarily reaching an explanation. As Bruno Latour (2007) claims, if the description is good enough, the explanation is redundant.

However, there are a number of issues that stand out in terms of the *specific* issues faced by CLL patients that are worth drawing attention to briefly in this overall conclusion. The heterogeneous nature of the disease with its multiple possible routes of progression and outcomes, and its ability to evolve along its trajectory make this a particularly slippery disease to live with and treat. In the context of this research it provides a double-articulation of multiplicity as a disease object, already having multiple identities in addition to the multiple enactments that constitute any disease. From the point of view of living with it, the constant uncertainty adds to the sense of *liminality* that many of my respondents reported and was raised by Evans and colleagues in their insightful paper on living with CLL, 'Invisible, Incurable and Inconclusive' (2013), explored as a 'Translation' narrative in the Diagnosis chapter. Often not requiring immediate treatment, presenting with a slow and insidious progress that can quickly become aggressive and require immediate treatment, or indeed never require treatment, this is a disease that locates people in a strange and unpredictable space between grave illness and relative health. Whilst this often gives CLL patients longer to research their own disease, and form long-term relationships with other CLL patients online, many respondents felt themselves outside of the cultural spaces and narrative possibilities reserved for those living with acute cancers, reflected in the attitudes of those around them, but most notably in their clinical relationships. Here, the significant amount of feedback indicating dissatisfaction with the amount of attention and information provided by some clinicians on diagnosis and beyond was cause for concern.

Numerous patients report having moved to different doctors when their online learning has revealed perceived inadequacies in the clinical relationship, and others have worked with their clinicians (where willing) to discuss what they have learned and contribute actively to their treatment decisions. Both network effects demonstrate how online narrative circulation spills over into the bricks, mortar and examining couches of the clinic and that, as some of the Translations of clinician-led narratives in this work have shown, has material effects on time and resources as well as sometimes influencing trajectories of care.

The rapidly changing treatment environment for CLL and the move towards more personalized prognostics and treatments following the sequencing of the human genome make it a particularly interesting disease to explore currently. CLL has moved fairly rapidly over my period of research from being regarded as a 'Cinderella' chronic cancer of elderly, to a major player in contemporary haematological research with the advent of the BTK and Bcl2 inhibitors. The range of complex research papers circulating online and the efforts of a number of key network actors to circulate and translate them is a major themes in my work, as are the global inequalities in access to new prognostics and treatments. As cancer care generally moves towards a world of individually tailored and, in many cases, highly expensive novel therapies, inequalities in access will be inevitable.

This work has demonstrated how networked, informed patients have a keener understanding of how to source information, trials, and CLL expert clinicians. It has also demonstrated networked activity surrounding narratives of both biotech and pharma industry's roles in drug

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innovation and production, and of the regulatory and funding processes that accompany any new drug's journey to market. The work has also shown however that, despite all of this knowledge and organized advocacy where it occurs, some people never get the drugs they want or need.

Across the issues faced by CLL patients, it becomes clear that highly informed network actors are much more aware of what they might be missing out on where, despite their best efforts, knowledge doesn't necessarily translate to access to new treatments or expertise. The cost of and restricted access to novel therapies is a major issue for CLL patients, and is likely to become a major issue for all cancer patients and the health services that care for them. This work has shown some of the tensions that exist between the pharmaceutical industry's aggressive push to market, regulating for safety, and acknowledging that access to these new drugs can literally sit between life and death for a number of CLL patients.

Wilking and Jonsson's (2005) observations on the inequalities in regulatory processes Europe concludes that slowing down the traffic of novel agents into the marketplace definitively costs some patients their lives. My work has suggested further exploration of the psychological impacts of this on patients undergoing traditional treatment and care against a backdrop of hype for future, less toxic treatments. Jeff Sharman's pertinent observations that in the US, around 10% of patients are treated at the large research centres by CLL experts, raises serious questions for the 90% who aren't, and hints at a degree of elitism. Online studies of this nature

have the potential to make visible the experiences of some of them at least, and explore what happens to 'expert' patients treated in general departments at smaller regional centres.

My original outline plan for the themed sections included a 'Survival' chapter, exploring some of the more general issues faced by CLL patients simply getting on with their lives in the moments between diagnosis, prognosis and treatment. Feedback from patients included observations on the impact of this disease on their sense of time, identity, spirituality, and relationships. Although I have threaded as many observations as I can through the various sections, time and space unfortunately has not allowed for inclusion of a dedicated chapter here. This is an area I intend to work on in the future, particularly as the issue of cancer 'survivorship' becomes more pertinent in cultures where the incidence of cancer grows ever higher<sup>108</sup>, as do the means to treat it more effectively in many cases.

I have argued that digital pathographies when read as circulating objects of CLL that intersect with a broad range of alternative narrative objects of the disease online have the potential to bring bodies, feelings, liminal spaces, science, technology, hardware, spirituality, politics and a whole lot more together into hybrid, collaborative and open-ended narrative acts with real power to exert significant material effects on the actors involved. These actors and their accompanying narratives (including those of artefacts such as technologies, illustrations and charts) engage in potential translations that serve to expand the network and confirm nodes or

<sup>108</sup> According to Cancer Research UK's worldwide cancer statistics, 14.1 million new cases of cancer were recorded in 2012, and 8.2 million cancer deaths globally in the same year (Cancer Research UK, 2012).



attractors within networks. Translations necessarily lead to circulations within the system or network as actors work the net. In my case, of course, this is literally the case as the context and the geography are constituted by online or internet-based communities.

As well as having the positive potential to enable, empower, include, enlighten, and broaden perspectives (as respondents have demonstrated), exposure to multiple circulating narratives in CLL networks can also (as respondents too have shown) terrify, exclude, anger, confuse or frustrate. Some may reasonably ask what use knowing where we are located in relation to other parts of the CLL machine is if that knowledge doesn't easily translate into the power to make it work differently for us, in the case of access to new treatments and prognostic testing for example. The omniscience gained by networked CLL patients can serve to inform them of global treatment advances and the experiences of others within that map, but the work has shown that knowledge hasn't always equated to power, or to staying alive. The fact that expectations raised from patients' initial forays into online learning are not always met by the treatment they receive once in the care of a consultant is a pertinent issue for CLL patients using the internet across all stages of their disease. It draws attention to the dissonance sometimes experienced between globally networked knowledge flows and locally delivered care, and how to manage the psychological impact of a surplus of knowledge that doesn't translate to control has been a major issue for some patients in this study and warrants further research.

## **Methodological Innovations**

Methodologically, I set out to test out the application of object-oriented approaches to disease inspired by the work of Mol (2002) on atherosclerosis, and Law and Singleton (2004) on liver disease – both grounded in the wider perspective of Actor-Network-Theory (ANT) - in clinical and offline settings, to CLL in online settings using an auto-ethnographic/pathographic approach typical of ANT methods. My work draws clearly on the trails they have blazed and the traces they have left in looking at disease as a concatenation of multiple enactments, held together by objects that remain recognizable in some ways as they shape-shift and leap across disciplinary and experiential boundaries. It also deviates from them in choosing to study the narrative inscriptions of a disease as they circulate online, to do that as an existing member of the networks they flow around, and to locate my research openly as a network actor or node in its own right. In that sense, this work is innovative, and has the potential to contribute to the fields of digital disease research, and object oriented methodologies in general.

This is just one version of one map of a global territory as it evolved over four years however. It is not intended to be read as *the* network map of CLL use online, production of which would take a lifetime, and still only qualify as a singular version of multiple possibilities. Future researchers might adopt a similar approach to trace a particular document, set of documents, follow a particular actor, or focus on a specific node for example. Focus can be placed variously on process, flow, identifying successful and unsuccessful networks and what holds them together or otherwise, identifying actors, network effects, and key matters of concern in

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network narratives. In this work I set out to sketch out this (relatively) small territory of CLL online in as much detail as I could.

Perhaps the most challenging aspect of that has been designing a coherent and legible structure for presenting such a complex assemblage of data in a form that prefigures my ontological approach. Starting with the problem of where to put my narrative self - too much autopathographic narrative and the object of my *own* CLL offers an over-is privileged account; none at all and I disingenuously elide what drove the research in the first place (see Methodology chapter for my responses to the Research Committee in this respect). Trying to position my own narrative as an object is of course always going to be contentious, as I write and live with CLL very much as a subject. However, my approach of positioning my subjective narratives as objects among and coming into contact with many other circulating narrative objects feels to me as if it has worked. I will leave other network users to judge that in the hope that this thesis becomes a key circulating object in time within the community I have studied.

The issue of how to organize the data as a narrative thesis has been another major challenge. Adopt a standard social sciences structure and I am forced to abstract my findings into straightforward analysis enslaved to a teleological endpoint, follow the almost completely unbracketed, dead flat, ANT poetics of experimental authors such as Tan Lin in Heath, and I risk alienating all but the most committed of readers. Ultimately, I settled on the hybrid approach of layering selected fieldwork examples of key circulating narratives and their intersections through the Translation sections with relevant literature in the field through the Perspectives

sections.

Threading voices from the survey throughout all of the sections is a way of holding the key translations and existing research perspectives together with multiple personal narrative enactments of CLL. My aim has been to achieve some degree of narrative coherence whilst positioning the reader to confront CLL online as a series of multiple narrative enactments whose various intersections play out on each other. I hope that I have shown how the individual everyday personal narratives of CLL intersect with each other and with the institutional inscriptions of CLL to make novel, and sometimes powerful narratives of change.

## **Chapter Summary**

I have argued that narrative construction in online communities takes place within a range of additional information-seeking behaviours, where alternative CLL narratives such as research papers, lab results, news stories, pharmaceutical press releases, and the experiences of other patients can end up shaping the shared stories of individual CLL patients. Given the range of narrative objects of CLL that circulate in the networks, it seems that perhaps internet communities are as much *inter-objective* as they are *inter-subjective*. This draws on a Deleuzian interpretation of culture as a material force in which text operates as just one actor in a broader network, and is not privileged as a locus of meaning in its own right: "...here the cultural text itself, the narrative, is not to be explored in terms of representation but in terms of

how it performs, acts upon us, or materially produces an 'effect' (Bassett, 2007:23).

By exploring the intersection of circulating narratives of a single disease online from a perspective of their material effects rather than analyzing them primarily as units of representation, I have located them as *inscriptions* of the practices enacted by the individuals, organizations and institutions producing them, and putting them into circulation. In doing so, I believe this study has put into practice an innovative approach for studying disease and its narrative performances in online support and knowledge exchange networks, revealing complex networks of intersections among these multiple narrative inscriptions of CLL online. It has identified some of the key actors and narratives involved in that process, and demonstrated some of the network effects produced when they come together. It has never been my intention to reduce those effects simply to observing the collective potential for patient empowerment generated in online communities, although that is certainly *one* of the effects among a number of others noted throughout this work, and one that as a CLL patient myself, I am pleased to observe.

It is important to remember that whatever this work might have shown about enactments and practices of CLL online, and whatever might be learned from that about the concerns of all parties involved with producing CLL as a disease we recognize, understand, treat, fund, regulate for, live with, and die with, it cannot account for those who remain *outside* the online networks I have turned my lens on here. To take the lens away from the small territory I have explored in such fine detail here is to recognize that those not inhabiting it, and therefore not accounted

for in this work, constitute almost certainly the majority of current CLL patients and their clinicians globally. Given some of the more positive observations made about the potential for patients to take more control over their own illness narratives in online networks, maybe the biggest challenge is to turn more patients from 'centred' to 'networked', and to help more clinicians to understand the implications of that. More clinicians in the CLL support networks online would certainly expose the medical profession more broadly to what it means to do CLL online, and to understand where their patients are, or might be located within circulating inscriptions of disease outside of the clinic setting.

This work has raised a number of issues surrounding lives with CLL as read through online narratives. I have made my own suggestions for further research, but in the multiple narratives offered here, my hope is that readers may see other questions that need addressing. I have worked throughout with the philosophy that "The overall aim of a multi-voiced form of investigative story telling need not necessarily be to come to a conclusion. Its strength might very well be in the way it opens questions up." (Mol and Law, 2004:17). As this work continues its journey as a CLL network actor, I hope that strength is realized.

## **Potential Shortcomings and Suggestions for Future Work**

I have worked hard to overcome the potential shortcomings of this work but, as with all research projects, I am aware that some remain. I will address those briefly in this short postscript.

As stated, the multi-layered narrative approach of presentation is a methodological gesture towards encouraging readers to adopt the position of actor network theorist in the reading process. The differing enactments of CLL online are, as exemplified to some extent here in the 'Translations' sections, wide –ranging and diverse. They tap into an equally broad range of potential contextual observations as set out in the 'Perspectives' sections. It has not been my intention to abstract or draw definitive conclusions on the Translations through the Perspectives (or 'explain' the enactments through the theoretical frames in other words). Rather, I have sought to present the contextual work as further layers of enacting disease in the broader cultural sense – as a means of asking further questions about what it means to do disease in online contexts rather than providing definitive 'answers'. There is always the potential that, particularly for readers not familiar with the ontological stance of Actor Network Theory, this approach may seem frustrating and/or confusing. My hope is that the expository work invested in the Methodology section makes my intentions and rationale for my narrative choices and structuring clear, but I am aware of the potential risk of alienating readers. This is particularly pertinent in the case of a thesis which such multi-disciplinary reach and potential significance. Throughout the work, I have strived to create a balance between the politics of

research methodology and form, and a desire for the work to remain accessible to the multiple actors making up the CLL community that the work ultimately sets out to serve, represent, and inform. In attempting to address both form and content in meaningful ways, it is inevitable that this iteration of the work may itself need a degree of ‘translating’ before it is circulated in various forms into some of the distinct communities of actors it describes. As the author, I see that not as a failing, but as an inevitable outcome of the research’s own position as a network actor meshed into varying broader networks, and potentially subject to multiple translations in its own right (see appendix 15 for examples of varied iterations of the work currently in circulation, including a copy of a paper published in the online proceedings of a conference on chronic illness (2012), a presentation of elements of the work given at a pan-European CLL advocacy planning meeting (2014), an e-mail exchange with a major UK Leukaemia and Lymphoma Charity using data to advise on the tone and content of CLL patient support literature, various videos of me talking about the work in circulation throughout the CLL networks, and a book chapter for an edited Medical Humanities collection currently in press).

I am aware that some readers not familiar with ANT may feel they have been thrown rather unceremoniously into the deep end of the field. I had to make a decision about how many of my allocated words I wanted to devote to explaining ANT itself in relation to my desire to do justice to the significant amounts of novel data I have uncovered with the work. ANT is a well-documented methodological approach, and I hope that the necessarily circumscribed descriptors, outlines, and references I have provided give the reader enough of a framework to allow them to feel comfortable with the complex and often baroque assemblages of narratives



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that the work presents them with from the outset (or at least to feel comfortable with any potential discomfort as part of the process of engaging with an ANT study of this nature). As a researcher, I felt the weight of my responsibility more strongly aligned towards representing my respondents and the narrative translations selected than to the task of re-iterating in time-consuming methodological detail that which can easily be found elsewhere. I hope I got the balance right in this respect, but again appreciate a possible need to adjust that balance in future, and more audience-specific iterations of this work.

The large amounts of data gleaned, and word-count restrictions made it difficult for me to work with phenomena observed beyond the thematic sections of Diagnosis, Prognosis, and Treatment addressed herein. A significant amount of online narrative circulation pertains to the business of simply 'surviving' or living with CLL and, inevitably in the case of an incurable hematological malignancy, dying from the disease. These important experiences are addressed to some extent in appropriate sections of the thesis, but there is much to be learned from a closer and more nuanced mapping of the themes of 'Survival' and 'Dying' specifically in my opinion. To that end, it is my intention to work this thesis up into a book in which both of those thematic areas will be mapped as dedicated additional chapters.

Finally, and as addressed in the Summary section of this chapter, this work represents the voices of CLL patients who have, at the very least, gone on line to respond to my 'In Our Blood' online survey. It is a study of online narrative circulation, and samples some of the actors involved in those networks. Although I have asked respondents about their practices, and

attitudes to online sharing in relation to their disease, and have made some observations about the more negative experiences and resistant attitudes expressed by some survey respondents, the work can make no claim to speak for the presumably significant amount of CLL patients *not* using online resources at all. In terms of representation, the work is also restricted largely to the English-speaking CLL patients using the CLL Support networks selected for the sample.

Whilst my observations apply to a relatively large-scale sample group for a one-woman-led research project, I am aware that further work needs to be done in exploring to what extent any findings might be meaningfully extrapolated to those sections of the CLL community remaining outside the remit of this thesis. It is also important to work towards understanding how those patients (and other CLL actors) currently not engaged in the kind of knowledge exchange, advocacy, and often demonstrable empowerment demonstrated through this research might be encouraged to engage in the future.

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# Appendices

Appendix 1: TouchGraph showing Available Data

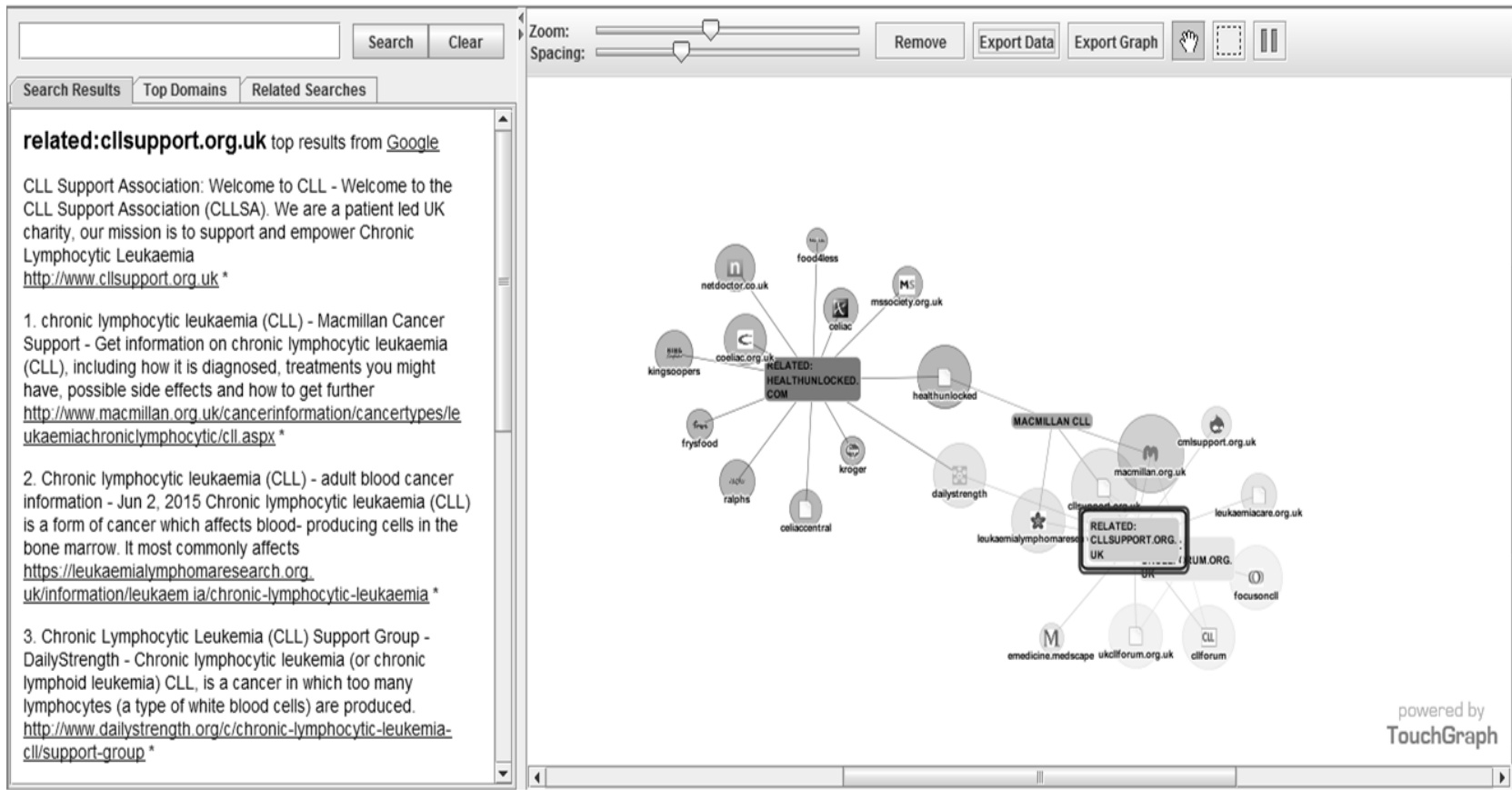


Figure 41: TOUCHGRAPH (2015) network connections and data for Macmillan CLL [Network Map]. [Online] Available at: <http://www.touchgraph.com/seo/launch?q=macmillan%20ccl> showing search results and graph for the initial search term 'Macmillan CLL' [Accessed 06/08/2015].

Julia Kennedy

## Appendix 2: Initial Invitation to Participate

Posted by [juliak](#) on

11-19-2012 6:54 PM

Hello - and hope everyone is doing okay,

I'm writing to you all today to ask if you would consider giving your vital input on my doctoral project "In the Blood" looking at how the CLL community gain knowledge and support from the internet.

I am giving a talk on my work at the Cardiff meeting on 30th January, 2013 alongside Professor Chris Fegan and Dr. Chris Pepper who will be talking about their clinical and research work. Some of you may have read my introduction to the project in the recent CLLSA Newsletter. If not, here's an extract:

*"In the Blood", my doctoral project, explores an online support community as a "hub" of knowledge and support exchange. From complex medical research papers to individual accounts of living with the disease (and much in between), the project will document the various stories that come together in the online support community, enabling users to make collaborative sense of a chronic disease that shapes our lives. Apart from identifying the key themes that occupy the lives of those living with (and around) CLL, the project looks at the relationships between research, clinical, and patient perspectives in the dialogues of support communities. How are we translating and utilizing the advanced information at our fingertips? How are we supporting and educating each other? How are we contributing to raising awareness of the disease? What impact is this having on our relationships with our clinicians and carers? Through this approach I aim to show how biomedical research, clinical management, and popular cultural beliefs about what it means to live with cancer translate to everyday experience for those of us living with CLL."*

I think that work like this is fundamental to understanding how we gain knowledge and support about our disease. CLL remains relatively under-researched in this respect (unlike breast cancer for example). Very few researchers of the communication networks surrounding disease actually have the experience of living with the disease. As a member of the community, a CLL patient, and a researcher, I think I can change that with *your* help, and I am proud and pleased to have the support of CLLSA who have read my proposal, and research paper.

If you are interested in being part of this work, please take a look at my blog

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<http://julesk-inourblood.blogspot.co.uk/>

The blog explains the rationale behind the work, sets out information about how to give informed consent to being part of the project, and gives you information about how I would protect the privacy and anonymity of any input you consented to me using. This PhD project has been through a rigorous ethics process with my University, and has been passed by the committee (who commended it for breaking new ground for online research ethics). I have also informed Macmillan about this work through the site's channels for communicating research projects within the online community.

If you have any further queries after reading the blog, please message me, or add a post to this thread. **Please remember, this community is as much a lifeline to me as it is to everyone else here, so my presence as a trusted member, and your continued sense of comfort and safety in using the site are my primary concerns.** If this research compromises that in any way, I will adjust it accordingly, or take it elsewhere.

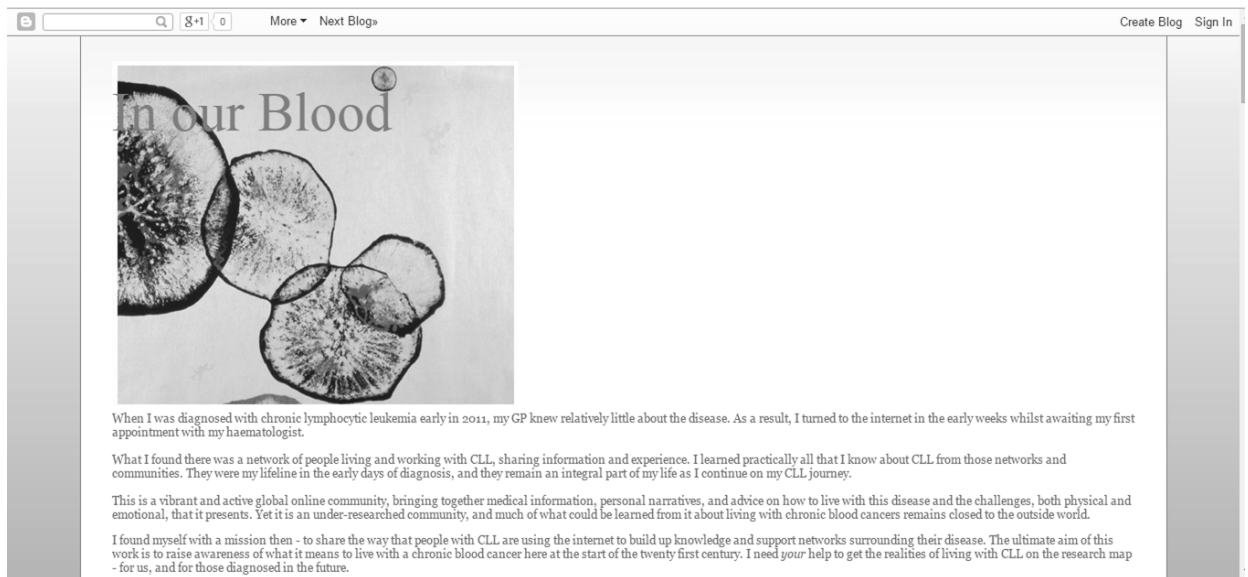
However, between us, I think we have so much to share that could impact on the way that the clinical and academic worlds understand what it means to live with and communicate about CLL. If you would like to be part of that adventure, I give you my absolute word that I will treat any postings or observations you consent to me using as the precious things they are. I also give you my word that if you don't want your contributions used to inform this research project in any way, that they *absolutely* will not be.

Have a think about this, read the information, and please get back to me with your thoughts or any comments. If you have any problems accessing the link or navigating the information there, please let me know asap.

Jules

### Appendix 3: In Our Blood Blog Screenshot and URL

Showing how link from initial invitation (Appendix 2a) gives respondents access to further information about the project on the blog site.



**Figure 42: JULESK (2013). “In Our Blood” Blog set up to inform participants and provide information and consent forms [Screenshot] 02/01/2013. Available at: <http://julesk-inourblood.blogspot.co.uk/> [Accessed 02/01/2013].**

Feedback indicates that people found this approach useful for reading more about the project, without me having to overload the invitation to respond with excess information that might have proved off-putting in the first instance. Interestingly, those people who had further queries tended to contact me directly rather than posting to the blog. In that sense, the blog didn't really function as a dialogic space in its own right as I had initially anticipated. However, it certainly functioned successfully to mediate information and ultimately strengthened the



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research as a network. There are a number of potential reasons for the seeming reluctance to post to the blog itself including: privacy/confidentiality; unfamiliarity among respondents with the blog format; maintaining existing lines of communication with me through support sites/private messaging among those respondents already in dialogue with me online; and my own willingness to communicate with respondents through their preferred channels.

Further research into using blogs as a means of disseminating information and communicating with potential research respondents would be useful in this context.

## Appendix 4: Response to Potential Respondent



Posted by [juliak](#) on

11-22-2012 9:22 PM

In response to your initial misgivings around confidentiality and feeling studied, I'm happy that you've raised that issue. This is of course one of the main areas I've had to focus on in the year long negotiation of rigorous ethics processes that I've been working on. Confidentiality is absolute - I'm not using anything that people don't consent to - quotes which people have consented to being used will be anonymized if the author wishes (although many people like to "own" their published quotes and get upset if their name is changed or replaced with a number). As far as being studied goes, I don't see myself as "studying" individuals in the community. I'll explain why.

Firstly, I'm not coming in from the outside to study the community in a 'colonial' manner - I'm already a member, and I joined because I needed the support and knowledge I get from the community to help manage my own life with CLL, and not to do the research. I was interested in looking at support communities for cancer patients on the internet in general when I joined, but got interested in how this community deals with knowledge exchange and support after joining because I think it does something quite different from other CLL communities that I am a member of. If I say something next about what it is that I think we do here that make those principles worth sharing with the wider world, that might also help answer your next questions about what it is *exactly* that I will be looking at within the group.

What I noticed from the outset here was an incredibly sophisticated approach to circulating a whole range of other information sources about CLL on the site. These range from complicated clinical research papers, information from alternative CLL websites, reports from clinical consultations including blood results, bone marrow biopsy results, scan readings, to newspaper reports about CLL celebrities such as the discussions about Clive James and the Daily Mirror feature on him that provoked a lot of discussion in the community a few months back and so on. What I'm interested in here is how those various stories or narratives of CLL,

be they scientific, clinical, educational, or popular cultural, find their way into people's own stories of their everyday experiences of living with CLL.

In this community, we translate a vast range of the circulating information that defines CLL into our own experiences. I'm interested in tracing all of the stories back to their origins (science, news, fund-raising campaigns, clinical) and then looking at how they are translated into the experiences of those community members who are happy to contribute. An example might be taking an illustration from "nature" magazine that shows Zap 70 as a branch amongst many others, then looking at a clinical research paper on the significance of Zap 70 in CLL prognostics, relating it to say Chaya Venkat's translation of the Zap 70 debate over on CLL topics, then looking at how we in the community relate the issue of knowing about our genetic mutations to our real lives (all of those texts and sites can be traced back from this community). I'm using a method known as Actor Network Theory to achieve that (a method designed by Bruno Latour to explore the way that science and scientists produce knowledge).

That is just one example, but it demonstrates how the community and our responses are just one part of a much bigger map of connections that join the scientific (in this case) to the everyday realities of knowing and living with this disease. For the purposes of this work, the community is the "hub" where a vast range of different narratives about CLL come together through the experience of the members. The work will also have an element of autobiographical writing about the disease from myself, and how I've come to know and live with it through what I've learned. That will be layered with all of the other texts that we learn from, and quotes from those who are happy to be involved under the following headings (which represent the main themes that concern those living with CLL emerging from my own experience and other stories I have encountered about living with CLL to date):

Diagnosis (how we understand it and how that feels); Prognosis (lots here about the impact of all the new research and treatments on our expectations); Living well with CLL (coming to terms with the impact of the disease on our lives); Impact of CLL on our perception of time (watch and wait and its implications for our view of the future); Relationships with others (impact of the disease on our connections with friends, family, and the rest of those we come into contact with).

If you're still here (I can't answer all the questions you've asked me without explaining them all clearly, so hang in there), you should be able to get a clearer picture of what I'm actually doing, and what my aims are by now. It should also become clear that I'm not actually looking at dynamics/hierarchies/roles of individuals

in the community - but at the way we are linking and circulating information, and translating it into our everyday experiences. I need some examples of that translation, but I don't need to look at *everyone's* contributions for this to work - it's not an ethnography of the community itself, but of the disease as it is represented in the community (if you're interested in this method see AnneMarie Mol's excellent book "The Body Multiple" which is an ethnography of atherosclerosis conducted in a hospital - I think you would really enjoy it). There is also a book by an academic called Jackie Stacey entitled *Teratologies* - the story of her own experiences with cancer that does something similar... Essentially I'm doing the same for CLL, but online, and - hugely importantly in my opinion - researching *our* disease from the inside out. There is so much written about cancer by people without cancer - it is part of my methodological politics to change that.

Finally - will I "contaminate" the data? It's another good question, and one my ethics committee asked. They were very positive about my response that I'm not making any claims to be objective in the positivist sense in this research because I am a native researcher - exploring the world I now live in through narrative associations, and through a significant element of my own autobiography. My presence here as a person with CLL is *fundamental* to the politics and design of the project. I get to write enough in this work about my own experience, so I don't need or want to influence the discussion on the site according to my research aims. Ultimately my PhD will be the story of 4 years of living with CLL, how I have come to understand it, and what I have observed about how others have come to understand it - all focused on all of the information and some of experience that converges at the "hub" of the Mac site...

Julia Kennedy

## **Appendix 5: Revised invitation**

jibs60

29 Dec 2012

Hello,

I hope that you have had an enjoyable Christmas holidays, and still have some energy left to celebrate as we head into the New Year...

I hope you don't mind me messaging you personally, but I'm looking for volunteers to contribute to my Doctoral Project 'In our Blood', looking at the way those of us living with CLL make sense of the impact of the disease on our lives through all of the different perspectives we come across when researching the disease online.

When I was diagnosed my GP had little knowledge of the disease. He was unable to answer many of my questions and told me to go away and "look it up on the internet". It was here that it became clear to me that "CLL" as we understand it is a disease constructed out of many perspectives, some mainstream and rooted in biomedical research and clinical practice, some tied into popular cultural belief systems about disease, others marginalised and "alternative", and many drawing from biographical autobiographical experience as we negotiate our own perspectives in relation to those already out there.

My project 'In our Blood' was born shortly after my diagnosis. The work traces the networks and associations between all of the different perspectives that come together both on and off-line to produce knowledge of a disease. The whole is looped into my own autobiographical narrative of

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what it means to live with this disease, and refers out to the biographical experiences of others through postings, blogs, videos etc. This is where I need your help to get as many perspectives from others living with CLL into the work...

I am particularly interested in drawing on people's experiences of:

Diagnosis (what it feels like to get the diagnosis, and how we deal with it)

Prognosis (what resources we use to deal with that - how research and other patient experiences affects our expectations)

Learning to Live with CLL (how we adjust our lifestyles and attitudes, and what resources we draw on to help with that)

How a diagnosis of CLL affects our sense of time (I guess this one is about the impact of an increased sense of mortality)

How having CLL impacts on our relationships with others (what happens to existing relationships with family/friends/colleagues - do we come to feel like 'strangers' in our own lives, and how do we deal with that?)

I would be delighted if anyone on this site would consider allowing me to use some of their own perspectives on living with CLL in my work. If not, no worries, and you can be sure that no dialogue we have online or elsewhere will find its way into my work. I am a fellow CLL traveller first and foremost, and my research is secondary to that (although I believe it to be important work that can benefit all of us living with cancer in some small way).

For those who are interested in contributing, I would be happy to use quotes and excerpts from the blogs and postings online on this forum pertaining to the above issues. This site is a rich source of experience and sharing of the fundamental issues we all face in learning to live with CLL. However, if people would prefer to write something privately to me about their experiences rather than giving

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consent for me to use blog postings or responses, please let me know, and I'll send some questions for you to respond to at your leisure...

I launched a blog to explain the work to respondents in an online support community for people with CLL a while back:

[julesk-inourblood.blogspot....](http://julesk-inourblood.blogspot....)

If you are interested, perhaps you could take a look at the information, download and read through the consent forms linked to the site under the Information and Consent Forms for Downloading heading on the right hand margin, and message me back either through this site, or on [julia.kennedy@falmouth.ac.uk](mailto:julia.kennedy@falmouth.ac.uk).

You will need to confirm clearly in writing the following (just copy and paste into your response, deleting options as appropriate):

"I confirm that I have downloaded a copies of the participant information sheet and the consent form to keep, and have read and understood them. I am willing to allow my postings/blog entries/e-mail interview responses (please include or delete as appropriate) to be used in the research project 'In our Blood'. I would prefer my contributions to be cited anonymously/attributed to me personally (for which I will need your full name)/attributed to my online name (please include or delete as appropriate)."

I'm working with this online consent process at present as getting people to fill in hard copy forms and send them back to me is proving tricky and can create problems for those wishing to remain anonymous.

Please get back to me if you would like to participate in any way, or if you have any questions about

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the work.

I'm presenting a paper on the project at the Cardiff meeting of the CLLSA on 30th January. The work has been through a rigorous ethics committee process and gained full ethics clearance from my University (University of the Arts London/Falmouth University). It has also been before the committee of the CLLSA and has its full support, and has received expressions of interest from the Lymphoma and Leukaemia Research Organisation.

I really look forward to having the privilege of working with your thoughts and experiences if you are willing to share them.

With kind regards, and wishing you a fine New Year ... Julia

e-mail: [julia.kennedy@falmouth.ac.uk](mailto:julia.kennedy@falmouth.ac.uk)

## **Appendix 6: SurveyMonkey Consent Form**





This page outlines the aims of the research project you are being asked to contribute to, provides information on your expected role, the security of your data and issues of confidentiality, and gives details of where further information can be sought. It is very important that you read and understand this information before consenting to take part in the project.

### **The Project and its Aims**

As a fellow CLL patient (diagnosed in February 2011), former nurse, and current communications academic, I am interested in what we can learn about living with disease from the networks of support and information available on the internet. There is a vibrant community of people whose lives are touched by CLL using the internet in many ways to share information and experience. This is where I have learned nearly everything that I know about the disease, and connected with others who live and work with CLL. Yet this remains an under-represented body in CLL research.

I am asking for your permission to use selected excerpts of postings or other contributions you have made to discussions about CLL online from archived material and over the coming months. These will be cited anonymously unless you state otherwise in this consent form. All you are required to do is to contribute online as you usually would and trust that, as a fellow CLL patient, I will handle any excerpts that I use

Julia Kennedy

carefully and sensitively. I want as many voices from the online CLL community as possible to be heard in this research.

As far as I am aware, this doctoral project is the first potential large-scale research into how patients and carers use online resources to make sense of CLL. The ultimate aim of the project is to enhance understanding of how the internet provides a hub of information and support to help us negotiate the challenges of living with chronic blood cancer in the twenty-first century.

### **Taking Part**

You are being asked to provide your consent to the researcher using selected excerpts of your online postings/contributions to CLL specific sites for the duration of the project which is due for completion in 2014. You don't need to do anything other than contribute to those sites as you usually would.

This form provides the means for you to access the relevant information to enable you to provide that consent in an informed manner, and to indicate your preferences for how you would like to be attributed in any published work arising from the project. Your IP address will not be stored, and information is encrypted and transmitted over secure channels.

### **How the Data will be Used**

The results will be submitted as part of my PhD thesis for University of the Arts London and Falmouth University. Work in progress will be written up for journal articles and conference papers. The project is receiving no external funding.

### **Risks**

Whilst every effort will be made to protect your identity and maintain your confidentiality, it is important to

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be aware that even anonymized quotes taken from online spaces can be traced back to any sites to which the searcher has access. This is a minimal risk in this research context, but you should be aware of it.

### **Benefits**

The benefits are long-term and are about contributing to improved understanding of what it means to live with CLL.

If you have any questions please contact me in the first instance at:

Julia Kennedy, Senior Lecturer, BA (Hons) Journalism, University College Falmouth, Treliever Road, Penryn, Cornwall, TR10 9EZ

[julia.kennedy@falmouth.ac.uk](mailto:julia.kennedy@falmouth.ac.uk)

Further information about the project, along with hard copies of participant information and consent forms to download if you wish to can be found on the research blog <http://julesk-inourblood.blogspot.co.uk/>

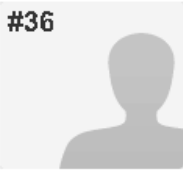
All of the following four statements need a response. By completing the form and submitting it you are confirming that you have read the description of the study, are over the age of 18, and that you are freely consenting to take part in the project.

This is not binding, and you are free to withdraw at any point simply by contacting the researcher

Sample Response:

'In Our Blood' Consent Form

SurveyMonkey

<b>#36</b> 	<b>COMPLETE</b> <b>Collector:</b> consent (Web Link) <b>Started:</b> Sunday, April 28, 2013 7:33:10 PM <b>Last Modified:</b> Sunday, April 28, 2013 7:37:17 PM <b>Time Spent:</b> 00:04:06 <b>IP Address:</b> 82.102.120.148
-------------------------------------------------------------------------------------------------	---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

PAGE 2: Your Consents

<b>Q1: I agree that I have read and understood the information about the project outlined above, and I would like to participate in the research study.</b>	Yes, I have read and understood the information, and would like to participate
<b>Q2: Activity Consents Please read the following statements and tick any that apply to your agreed level of participation in the project: I understand that I have given my consent for the following to take place:</b>	For selected examples of my online contributions to be used as data in this research project
<b>Q3: I grant permission for the data generated from my contributions to be used in the researcher's publications on this topic. Please select from the options below to indicate how you would like your statements to be attributed</b>	I grant permission for the researcher to quote me anonymously in published work, and understand that the researcher will provide a pseudonym.
<b>Q4: Entering your name in the box below, and submitting the form on completion indicates that you are freely consenting to participate in the project according to the preferences outlined in your answers to the above questions. It is important that I can match your consent to your online identity, so please sign off using the name or names you use online (indicating which sites they apply to if you use multiple online identities). There is no need for you to provide your full name in addition unless you wish to, or unless that is the name you use online anyway. Don't forget that this is not binding, and that you can withdraw from the project at any time by letting me know that you no longer wish to be involved.</b>	
Please enter the name/s you use online	casanova
Date	28th April 2013

Julia Kennedy

## **Appendix 7: Sample Messages of Endorsement/Support**

These have been copied and printed removing identifying details where appropriate in line with ethical guidelines for the project.

### **Message Received 6/12/12**

Dear Julia,

I am glad you have posted your Project on the Acor list, being one of the oldest and a very respected one, very well run.

I do not contribute as much as I used to do for many years, but I know most of the old members and when I give updates I get many mails in private.

Not sure if you have put your rresearch on the [www.clcfriends.com](http://www.clcfriends.com) and also the [clforum.com](http://clforum.com), both very respectable and both started by original members of acor that felt wanted more than just a list.

The original people of CLLSA we met through Acor in the first place, sadly several have now passed away but they stay in our memories and many were very influential in our beginnings.

I wish you well and hope you get many responses,

I am a User Representative for Thames Valley Cancer Network for Haematology as well as my local hospital in Swindon I find that it is now after 10 years that the UK people are using the internet more, you would be amazed by the comments I had rom a consultant 10 years ago talking about internet, we have to be tghankful for people like Prof. Terry Hamblin who really push patient influence and helped many people using the internet.

If I am fully honest I would rather be diagnosed with CLL over the last couple of years than when I did 10 years ago, it was hard work dealing with medics in those days, I can sit back and see the amazing progress we have made, I can see how in TVCN patients are welcome to be involved in many things and

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their influence is great. At Swindon we are going to produce a DVD for newly diagnosed patients, one other hospital in TVCN has already done it and proved very helpful.

I am busy the next couple of days but will do your survey and if you need any other help, please let me know.

Rest [sic] Regards

**Message received 11/02/13**

Dear Julia,

As a fellow reader of the CLL list – and also an academic - I was sorry to see that you have had to join the CLL community but interested to hear that you are developing this project. I was diagnosed at age 47 and after the initial trauma of getting such a diagnosis when one has children, have stayed off treatment for 15 years despite some rise in my WBC (now around 100k too) and drops in platelets.

I run a research unit on cancer prevention and early detection at XXX, part of which involves an interest in health communication and internet use. So if you were ever in London and wanted to visit, it would be good to meet up.

Best wishes

XXXXXXXXXXMA, PhD, FMedSci

Professor of Clinical Psychology

Director, XXXXXXXXXXXXXXXXXXXX

Department of Epidemiology and Public Health

XXXXXXX

XXXXXXX

Julia Kennedy

**Message : received 7/1/13**

Hi Julia,

It was great to read about your research project on the ACOR CLL listserv.

I've added you as a reader to my password protected blog, located

here: <http://revolvingat900milesanhour.blogspot.ca/>. There you'll find my husband's history, along with

a short overview of how the internet and web essentially provided him with many extra years of life.

Please be in touch if I can be of more help. I work in health research in British Columbia so am happy to be of any assistance.

xxxxxxxxxx

Victoria, Canada & one of the initial ACOR CLL listserv users

**Message received 30.12.12**

Happy to help but this all gets too complicated..

Remember CLL is a disease of OLDER people..!!

Have to have a Facebook account, or sign up to yet more rubbish e-mails..

Simplify and I will help..!!

Julia Kennedy

Happy New Year..

**Message received 6.1.13**

Please take a look at PatientPower.info, my blog and my book, The Web-Savvy Patient. I'd be happy to help you.

Best Wishes,

Andrew Schorr, Barcelona

***Andrew Schorr*** | *Founder and Host* | [andrew@patientpower.info](mailto:andrew@patientpower.info) | 206.973.7390 or +34  
622069835

***PatientPower.info*** | [Facebook](#) | [YouTube](#) | [Twitter](#)

(public site – and frequently mentioned key network node in research - so details not  
anonymized)



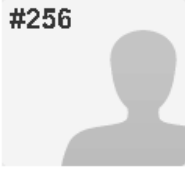
## **Appendix 8: Sample selection of completed 'In Our Blood' survey forms**

### **This appendix contains:**

Four completed survey forms.

Summary data visualization and % figures for quantitative questions 2-8.

Data summary for qualitative question 15 requesting respondents to identify any issues they felt I had omitted in the survey. This was an important part of the survey as it allowed me to consider themes and issues not identified in my initial fieldwork online, and thus not already represented in the themed survey questions.

<p>#256</p> 	<p><b>COMPLETE</b></p> <p><b>Collector:</b> In Our Blood: ...et Use Survey (Web Link)  <b>Started:</b> Wednesday, May 15, 2013 8:06:22 PM  <b>Last Modified:</b> Wednesday, May 15, 2013 8:27:56 PM  <b>Time Spent:</b> 00:21:34</p>
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PAGE 1: In our Blood

Q1: The Project and its Aims As a fellow CLL patient (diagnosed in February 2011), former nurse, and current communications academic, I am interested in the networks of support and information available on the internet. Consuming and sharing information online can transform our experience of illness. From working through the first terrifying stage of diagnosis, to becoming our own advocates, internet communications can play a key role. This doctoral project sets out to explore the way that patients and carers use online networks to make sense of CLL, with the broader aim of improving understanding of what it means to live with chronic blood cancer in the twenty-first century. As far as I am aware, this is the first potential large-scale project researching how people respond to living with CLL, and how they use the internet to make sense of their experiences. Taking Part I am inviting you to answer a few questions about living with CLL, and how you might use the internet to gain information and support with that. The survey is anonymous, secure, and responses can only be accessed by myself as the researcher and account holder. You should allow at least 15 mins to complete the form, depending on the length of your answers. You may partially complete the survey, and return to it later to complete if that is preferable. How the Data will be Used The results will be submitted as part of my PhD thesis for University of the Arts London and Falmouth University. Work in progress will be written up for journal articles and conference papers. The project is receiving no external funding. Risks There is no risk inherent in taking part in this survey. All responses are anonymous and cannot be attributed to any individual. Your IP address will not be stored, and information is encrypted and transmitted over secure channels. Benefits The benefits are long-term and are about contributing to improved understanding of what it means to live with CLL. How the Data will be Used The results will be submitted as part of my PhD thesis for University of the Arts London and

Yes

Falmouth University. Work in progress will be written up for journal articles and conference papers. The project is receiving no external funding. If you have any questions please contact me in the first instance at: Julia Kennedy, Senior Lecturer, BA (Hons) Journalism, University College Falmouth, Treliever Road, Penryn, Cornwall, TR10 9EZ julia.kennedy@falmouth.ac.uk You can also find further information about the project, along with hard copies of participant information and consent forms to download if you wish on the research blog <http://julesk-inourblood.blogspot.co.uk/> By clicking yes below, you confirm that you have read this description of the study, are over the age of 18, and that you freely consent to completing the survey and to your responses being used in the project described.

PAGE 2: How I use the internet to gain information about CLL

<b>Q2: Please tick any of the online sites below that you use to gain information and support about CLL.</b>	MacMillan online, CLL Global, Other (please specify) Ash
<b>Q3: If you use participatory sites (support group, listserv, facebook, YouTube), please indicate your level of participation</b>	I rarely visit or contribute to CLL sites online
<b>Q4: If you do post to online sites, please indicate what kind of contributions you make by ticking the relevant boxes below</b>	<i>Respondent skipped this question</i>
<b>Q5: If you don't actively participate in the sites you use, please indicate why that may be.</b>	Other (please specify), or feel free to expand on any of your answers above I don't find it helpful to read other people's treatment journeys. They do not usually come with a health warning up front and having lived with this disease for 4 years, through 3 rounds of treatment and a bone marrow transplant there is a degree of self preservation required. As such I don't post either as my journey has been tricky and I wouldn't say that helpful. Perhaps that will change if I reach a period of stability but not yet unfortunately. I use the Internet mainly for factual research on drugs, side effects, conditions & research
<b>Q6: Do you feel that your internet use surrounding CLL has made you into a more informed patient?</b>	Yes

<p><b>Q7: Do you think that having more information helps you to deal with living with the disease?</b></p>	<p>Sometimes, Please comment briefly - particularly if you answered "sometimes" Selective information but there is some degree of self preservation required. Why know and possibly worry about all the particular problems that can occur which may never happen to you. It doesn't always help especially when your focus has to become living in the present, this is particularly true during a transplant.</p>
<p><b>Q8: Does being more informed about CLL affect your relationship with your medical team?</b></p>	<p>Yes, I discuss what I have learned online with my Doctors.</p>

PAGE 4: Living with CLL: The Key Issues

<p><b>Q9: Diagnosis is clearly a huge challenge for those of us with CLL to come to terms with. Please make any observations about how you dealt with or are dealing with the challenge of diagnosis. If any particular online resource/s were or remain especially helpful to you, please identify them in your comment. If you were diagnosed prior to ease of access to internet support, please say something about how you gained information and support.</b></p> <p>Macmillan, leukaemia research</p>
<p><b>Q10: One of the key themes for discussion online around CLL is that of prognosis. Major concerns are expressed around who gets prognostic testing, and the effects of knowing our prognostic markers. Please make any observations about how you have gained information and advice to help you negotiate your own attitudes to CLL prognosis. If any particular online resource/s are especially helpful to you (or otherwise), please identify them in your comment.</b></p> <p>This is tricky, I was told the possibilities at initial diagnosis but didn't find out my own prognostic markers until after about a year of watch and wait and disease progression necessitated more tests prior to treatment. I am thankful as although I worried that year I honestly thought it would be easier than it has been. I don't think that knowing my markers any earlier would have changed my treatment or improved key short periods of remission. However it did mean I didn't worry about transplants and treatment as I didn't think that would happen.</p> <p><b>Q11: Please contribute any observations here about how you have negotiated the challenge of learning to live with CLL. This question is really about how we adjust our lifestyles and attitudes (both emotionally and physically), and what resources we draw on to help with that. Again - if any specific sites, resources or online activities have helped you with that particularly, or if you have used them to share your thoughts about this issue then please identify them in your answer.</b></p> <p>Still a work in progress I'm afraid. No answers to give really. I do see a counsellor at the Maggie's centre and have recently taken a course on mindfulness which is helping.</p>

**Q12: Time.** Living with a chronic illnesses can significantly effect a person's sense of control over their own time. This can be about issues such as needing to plan life around hospital appointments, treatment, and fatigue. The approach of "watch and wait" can bring uncertainty to life plans and visions of the future, as can remission length for those in treatment. Say anything you can here about how your own sense of time has been affected by your CLL diagnosis, again referring to any online resources that you have used to help with this where appropriate.

I have adjusted to living mainly in the present. I plan only in the short term and have accepted that things are often cancelled. It's very disappointing but I try and take pleasure from the small things that I do manage. The last few months have been good and I really hope this continues. Who knows?

**Q13: Relationships.** Some people report feeling like "an outsider" following a diagnosis with a serious illness. Use this box to comment on how CLL has made a difference to your relationships with others? What effect does it have on existing relationships with family, friends, and colleagues? Have you decided not to tell other about your CLL for fear of being regarded differently? Have you perhaps built new relationships as a result of your CLL? Please mention any online activities that you have used to work through these issues.

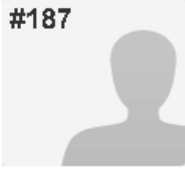
This is a mindfield... Especially after 4 years and the last 2 of continuous treatments. Everyone is tired of it, especially me. Some family members are great and some let you down, unexpectedly. I think it's usually as they find it hard to deal with. With telling people i mostly judge whether they are a good enough friend before I begin. Although sometimes its unavoidable, I find it hard to lie.

**Q14: New treatments and the future.** The CLL world is buzzing at present with news of new treatment protocols and new drug trials in the pipeline. Monoclonal antibodies have enhanced CLL treatment, and the human genome and subsequent cancer genome projects have opened up a "brave new horizons" of approaches to cancer treatments in general, with talk of a "cure" in sight. Please say a little about how these claims affect your attitude to your own CLL, and what online resources you use to keep up with them.

I feel very lucky that all this new research will hopefully mean I still have some options left if I relapse again

**Q15: Please comment here on any key issues or themes surrounding living with CLL that you think I have overlooked in my list.**

*Respondent skipped this question*

<p><b>#187</b></p> 	<p><b>COMPLETE</b></p> <p><b>Collector:</b> In Our Blood: ...et Use Survey (Web Link)  <b>Started:</b> Wednesday, April 03, 2013 11:19:07 AM  <b>Last Modified:</b> Wednesday, April 03, 2013 12:27:12 PM  <b>Time Spent:</b> 01:08:04</p>
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PAGE 1: In our Blood

<p><b>Q1: The Project and its Aims</b>As a fellow CLL patient (diagnosed in February 2011), former nurse, and current communications academic, I am interested in the networks of support and information available on the internet. Consuming and sharing information online can transform our experience of illness. From working through the first terrifying stage of diagnosis, to becoming our own advocates, internet communications can play a key role. This doctoral project sets out to explore the way that patients and carers use online networks to make sense of CLL, with the broader aim of improving understanding of what it means to live with chronic blood cancer in the twenty-first century. As far as I am aware, this is the first potential large-scale project researching how people respond to living with CLL, and how they use the internet to make sense of their experiences. Taking Part I am inviting you to answer a few questions about living with CLL, and how you might use the internet to gain information and support with that. The survey is anonymous, secure, and responses can only be accessed by myself as the researcher and account holder. You should allow at least 15 mins to complete the form, depending on the length of your answers. You may partially complete the survey, and return to it later to complete if that is preferable. How the Data will be Used The results will be submitted as part of my PhD thesis for University of the Arts London and Falmouth University. Work in progress will be written up for journal articles and conference papers. The project is receiving no external funding. Risks There is no risk inherent in taking part in this survey. All responses are anonymous and cannot be attributed to any individual. Your IP address will not be stored, and information is encrypted and transmitted over secure channels. Benefits The benefits are long-term and are about contributing to improved understanding of what it means to live with CLL. How the Data will be Used The results will be submitted as part of my PhD thesis for University of the Arts London and</p>	<p>Yes,</p> <p>Responses to this survey are anonymous. However, if you would prefer your responses to be attributed to you, please enter the name you would like me to use here          Angela</p>
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Falmouth University. Work in progress will be written up for journal articles and conference papers. The project is receiving no external funding. If you have any questions please contact me in the first instance at: Julia Kennedy, Senior Lecturer, BA (Hons) Journalism, University College Falmouth, Treliever Road, Penryn, Cornwall, TR10 9EZ julia.kennedy@falmouth.ac.uk You can also find further information about the project, along with hard copies of participant information and consent forms to download if you wish on the research blog <http://julesk-inourblood.blogspot.co.uk/> By clicking yes below, you confirm that you have read this description of the study, are over the age of 18, and that you freely consent to completing the survey and to your responses being used in the project described.

PAGE 2: How I use the internet to gain information about CLL

<p><b>Q2: Please tick any of the online sites below that you use to gain information and support about CLL.</b></p>	<p>MacMillan online, CLLSA Health Unlocked Group</p>
<p><b>Q3: If you use participatory sites (support group, listserv, facebook, YouTube), please indicate your level of participation</b></p>	<p>I never post online, but I regularly log into and read one or more CLL sites.</p>
<p><b>Q4: If you do post to online sites, please indicate what kind of contributions you make by ticking the relevant boxes below</b></p>	<p><i>Respondent skipped this question</i></p>
<p><b>Q5: If you don't actively participate in the sites you use, please indicate why that may be.</b></p>	<p>I worry that I may say the wrong thing or upset others on the site</p>
<p><b>Q6: Do you feel that your internet use surrounding CLL has made you into a more informed patient?</b></p>	<p>Yes</p>
<p><b>Q7: Do you think that having more information helps you to deal with living with the disease?</b></p>	<p>Yes</p>
<p><b>Q8: Does being more informed about CLL affect your relationship with your medical team?</b></p>	<p>No, I don't discuss what I see online with my Doctors ,</p> <p>If you answered "yes" please comment on how your Doctors react to this. If you answered "no", please write a few words explaining why. still on W&amp;W and doing fine - not had any real need to bring up any aspects yet... but sadly there is no consistency in who I see at the hospital (going every 3 months - its been 3 years in May - and seen possibly 5 or 6 different people in that time)</p>

## PAGE 4: Living with CLL: The Key Issues

**Q9: Diagnosis is clearly a huge challenge for those of us with CLL to come to terms with. Please make any observations about how you dealt with or are dealing with the challenge of diagnosis. If any particular online resource/s were or remain especially helpful to you, please identify them in your comment. If you were diagnosed prior to ease of access to internet support, please say something about how you gained information and support.**

At the time of diagnosis I went through the classic stages of grief, and wanted to research all aspects of the disease this was through the internet, through a document given to me by my GP and through booklets sent through the post from CLL Support Ass. and Leukaemia Care. It was a journey that felt like a rocky road at the start, but is now a much more stable ramble along - the information gained helped me to understand the situation and put it all into context, although some data left me feeling scared and worried for my future - with hindsight I think i was just looking to see when I might die from this - now I get on and live with it and the data esp from CLLSA Healthunlocked helps me to do that

**Q10: One of the key themes for discussion online around CLL is that of prognosis. Major concerns are expressed around who gets prognostic testing, and the effects of knowing our prognostic markers. Please make any observations about how you have gained information and advice to help you negotiate your own attitudes to CLL prognosis. If any particular online resource/s are especially helpful to you (or otherwise), please identify them in your comment.**

interesting question - prognosis at the start was definitely the key area of interest and I underwent a number of tests (CT scan etc) plus much more regular blood tests until it was established that my CLL was not too aggressive and we could sit back and wait and see what happened - but I got very little information/advice/support from the Doctors and therefore had to try and gain some understanding from what little I had picked up on from the internet - general and specialist sites. think it would be helpful if the Hospital gave a print out of relevant info on the results I have from investigations/guidance sheets - the language barriers have been a challenge too, none of the Docs speak clear English or seem to understand my questions.



**Q11: Please contribute any observations here about how you have negotiated the challenge of learning to live with CLL. This question is really about how we adjust our lifestyles and attitudes (both emotionally and physically), and what resources we draw on to help with that. Again - if any specific sites, resources or online activities have helped you with that particularly, or if you have used them to share your thoughts about this issue then please identify them in your answer.**

I have definitely learnt to live with CLL and that has a lot to do with the information I read on the internet - I see too how many people are much worse than myself and I feel relieved that I am still having an excellent quality of life - but having CLL coincided with the opportunity to set up a social enterprise which offers creativity as a form of therapy to anyone, especially those with chronic and mental illness - I think the positivity of my daily work and the amazing feedback and support of those we are helping, plus the adrenalin from the very hard work of running this enterprise has more than kept me going, but has spurred me on and helped me see CLL as almost a blessing!! strange... but true. I feel physically better now than I did 3 years ago. One separate challenge I have is being 52 years old and female - what is CLL and what is the perimenopause stage that I am in? no help given in this area yet - but I haven't particularly hunted for it yet.

**Q12: Time. Living with a chronic illnesses can significantly effect a person's sense of control over their own time. This can be about issues such as needing to plan life around hospital appointments, treatment, and fatigue. The approach of "watch and wait" can bring uncertainty to life plans and visions of the future, as can remission length for those in treatment. Say anything you can here about how your own sense of time has been affected by your CLL diagnosis, again referring to any online resources that you have used to help with this where appropriate.**

I have previously been in health related circumstances where my longevity have been questioned, so I was already one of those who 'live for the moment' and grasp life opportunities - so I was well placed to eventually embrace CLL and this aspect - it helps that I am really very well and hardly affected by it, therefore I am very much living every minute and making the most of it. I am encouraging others to make the most of the time we have, none of us know how much we have whether living with chronic illness or not. For me it focuses the mind, and again is really a blessing (I am not at all religious by the way) - I just get on with it, and maybe I am slightly in denial about what might be around the corner while I am doing so well.... time will tell. with regard to online resources - I use social media to promote our enterprise and encourage others to have lives which make use of time in a positive way - and have used online resources myself to see how others live with the condition

**Q13: Relationships. Some people report feeling like "an outsider" following a diagnosis with a serious illness. Use this box to comment on how CLL has made a difference to your relationships with others? What effect does it have on existing relationships with family, friends, and colleagues? Have you decided not to tell other about your CLL for fear of being regarded differently? Have you perhaps built new relationships as a result of your CLL? Please mention any online activities that you have used to work through these issues.**

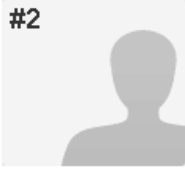
it was interesting at the diagnosis stage how people reacted - most were supportive and caring whereas just a few were dismissive and not at all caring (one was a best friend!!) another was an acupuncturist I have worked with in our project who offered treatments, but a number of times stated that she had looked into CLL (via her own GP and son training as a GP) who both stated that 'it was nothing' and not a serious condition to worry about, this upset me quite a bit and we almost argued over how it is to live with this condition which eats away at your emotions and body steadily and to me, is not 'nothing' - watching and waiting for something like chemo, is not 'nothing'. I also feel angry that medical people (in practice and being taught) can have this attitude - not helpful at all and implies a complete lack of understanding of the issues around chronic illness and mental health

**Q14: New treatments and the future. The CLL world is buzzing at present with news of new treatment protocols and new drug trials in the pipeline. Monoclonal antibodies have enhanced CLL treatment, and the human genome and subsequent cancer genome projects have opened up a "brave new horizons" of approaches to cancer treatments in general, with talk of a "cure" in sight. Please say a little about how these claims affect your attitude to your own CLL, and what online resources you use to keep up with them.**

ok, here I get quite lost. I have read about some of them but until i get to a stage where I need treatment I am just sitting back and ignoring it mostly - will it be available? will the NHS pay for new treatments? when will I need it? don't know.... so not worrying too much about it at this stage - what will be will be, and I just hope its the best that can be accessed at that time (I do wonder that my local Consultant(s) are fully versed in all aspects of CLL, i don't have much faith in them, which worries me). I use CLL Health Unlocked to keep an eye on comments about new treatments - interesting but not relevant to me at this stage - this is only because the alerts pop up daily and I see the references in the titles within the notification emails, otherwise I would not be researching this aspect from other sites.

**Q15: Please comment here on any key issues or themes surrounding living with CLL that you think I have overlooked in my list.**

*Respondent skipped this question*

<b>#2</b> 	<b>COMPLETE</b> <b>Collector:</b> In Our Blood: ...et Use Survey (Web Link) <b>Started:</b> Wednesday, January 02, 2013 8:11:47 PM <b>Last Modified:</b> Wednesday, January 02, 2013 9:05:26 PM <b>Time Spent:</b> 00:53:39
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## PAGE 1: In our Blood

**Q1: The Project and its Aims** As a fellow CLL patient (diagnosed in February 2011), former nurse, and current communications academic, I am interested in the networks of support and information available on the internet. Consuming and sharing information online can transform our experience of illness. From working through the first terrifying stage of diagnosis, to becoming our own advocates, internet communications can play a key role. This doctoral project sets out to explore the way that patients and carers use online networks to make sense of CLL, with the broader aim of improving understanding of what it means to live with chronic blood cancer in the twenty-first century. As far as I am aware, this is the first potential large-scale project researching how people respond to living with CLL, and how they use the internet to make sense of their experiences. Taking Part I am inviting you to answer a few questions about living with CLL, and how you might use the internet to gain information and support with that. The survey is anonymous, secure, and responses can only be accessed by myself as the researcher and account holder. You should allow at least 15 mins to complete the form, depending on the length of your answers. You may partially complete the survey, and return to it later to complete if that is preferable. How the Data will be Used The results will be submitted as part of my PhD thesis for University of the Arts London and Falmouth University. Work in progress will be written up for journal articles and conference papers. The project is receiving no external funding. Risks There is no risk inherent in taking part in this survey. All responses are anonymous and cannot be attributed to any individual. Your IP address will not be stored, and information is encrypted and transmitted over secure channels. Benefits The benefits are long-term and are about contributing to improved understanding of what it means to live with CLL. How the Data will be Used The results will be submitted as part of my PhD thesis for University of the Arts London and

Yes,

Responses to this survey are anonymous. However, if you would prefer your responses to be attributed to you, please enter the name you would like me to use here  
Hazel Mark

Falmouth University. Work in progress will be written up for journal articles and conference papers. The project is receiving no external funding. If you have any questions please contact me in the first instance at: Julia Kennedy, Senior Lecturer, BA (Hons) Journalism, University College Falmouth, Treliever Road, Penryn, Cornwall, TR10 9EZ julia.kennedy@falmouth.ac.uk You can also find further information about the project, along with hard copies of participant information and consent forms to download if you wish on the research blog <http://julesk-inourblood.blogspot.co.uk/> By clicking yes below, you confirm that you have read this description of the study, are over the age of 18, and that you freely consent to completing the survey and to your responses being used in the project described.

PAGE 2: How I use the internet to gain information about CLL

<p><b>Q2: Please tick any of the online sites below that you use to gain information and support about CLL.</b></p>	<p>CLLSA Health Unlocked Group, Other (please specify) CLL Support Group</p>
<p><b>Q3: If you use participatory sites (support group, listserv, facebook, YouTube), please indicate your level of participation</b></p>	<p>I actively post online about CLL issues regularly (more than six posts annually - please give a rough estimate of posting frequency in box below)</p>
<p><b>Q4: If you do post to online sites, please indicate what kind of contributions you make by ticking the relevant boxes below</b></p>	<p>I post about the physical and psychological impacts of living with CLL , Other (please specify), or feel free to expand on any of your answers above I am trying to set up a Devon/Cornwall support group and have talked to a Plymouth lady on the phone.</p>
<p><b>Q5: If you don't actively participate in the sites you use, please indicate why that may be.</b></p>	<p><i>Respondent skipped this question</i></p>
<p><b>Q6: Do you feel that your internet use surrounding CLL has made you into a more informed patient?</b></p>	<p>Yes</p>
<p><b>Q7: Do you think that having more information helps you to deal with living with the disease?</b></p>	<p>Yes</p>

**Q8: Does being more informed about CLL affect your relationship with your medical team?**

No, I don't discuss what I see online with my Doctors

If you answered "yes" please comment on how your Doctors react to this. If you answered "no", please write a few words explaining why. I am always aware of the limited appointment time. Also I listen to my consultant.

**PAGE 4: Living with CLL: The Key Issues**

**Q9: Diagnosis is clearly a huge challenge for those of us with CLL to come to terms with. Please make any observations about how you dealt with or are dealing with the challenge of diagnosis. If any particular online resource/s were or remain especially helpful to you, please identify them in your comment. If you were diagnosed prior to ease of access to internet support, please say something about how you gained information and support.**

I went to a CLL conference in Oxford last March.  
Also ordered DVD of Leicester conference in May.  
Before internet info, I was given a brochure by my consultant. I think we are very cut off in Cornwall for information. What about CLL people without the internet.

**Q10: One of the key themes for discussion online around CLL is that of prognosis. Major concerns are expressed around who gets prognostic testing, and the effects of knowing our prognostic markers. Please make any observations about how you have gained information and advice to help you negotiate your own attitudes to CLL prognosis. If any particular online resource/s are especially helpful to you (or otherwise), please identify them in your comment.**

My consultant has told me that I will probably need chemo drugs this year. I have avoided researching drugs, because I can only have what is available. Unless I take part in new drug trials, which again only depends on stage of disease and availability.

**Q11: Please contribute any observations here about how you have negotiated the challenge of learning to live with CLL. This question is really about how we adjust our lifestyles and attitudes (both emotionally and physically), and what resources we draw on to help with that. Again - if any specific sites, resources or online activities have helped you with that particularly, or if you have used them to share your thoughts about this issue then please identify them in your answer.**

I have made a Bucket list of things that I want to do. Last year I went to Scotland on a trip. Walking parts of the coastpath, not yet covered. Staying in interesting hotels, that I planned to stay in. The CLL support group have opened up information.

**Q12: Time.** Living with a chronic illnesses can significantly effect a person's sense of control over their own time. This can be about issues such as needing to plan life around hospital appointments, treatment, and fatigue. The approach of "watch and wait" can bring uncertainty to life plans and visions of the future, as can remission length for those in treatment. Say anything you can here about how your own sense of time has been affected by your CLL diagnosis, again referring to any online resources that you have used to help with this where appropriate.

I am in the watch and wait stage stage. My white cell count has stayed about 200 all last year. I look after myself, eat and exercise well. If I want a holiday or to buy something, I tend to do it regardless. Just off to Spain for three weeks, which is a regular January trip for vitamin D.

**Q13: Relationships.** Some people report feeling like "an outsider" following a diagnosis with a serious illness. Use this box to comment on how CLL has made a difference to your relationships with others? What effect does it have on existing relationships with family, friends, and colleagues? Have you decided not to tell other about your CLL for fear of being regarded differently? Have you perhaps built new relationships as a result of your CLL? Please mention any online activities that you have used to work through these issues.

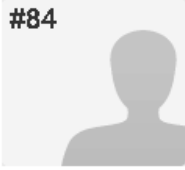
I feel extra sensitive, since being diagnosed. My husband has 3 monthly injections for prostate cancer, so we support each other. Relatives and friends are unaware of the effects of the disease, as it is less common. Long phone chat with a Plymouth lady and we will meet next month. Trying to build up a Devon/Cornwall support group. Only three people from Devon have replied. We need more brochures left out and contact in Cornwall.

**Q14: New treatments and the future.** The CLL world is buzzing at present with news of new treatment protocols and new drug trials in the pipeline. Monoclonal antibodies have enhanced CLL treatment, and the human genome and subsequent cancer genome projects have opened up a "brave new horizons" of approaches to cancer treatments in general, with talk of a "cure" in sight. Please say a little about how these claims affect your attitude to your own CLL, and what online resources you use to keep up with them.

I learnt about drug trials and bone marrow transplants at the Oxford conference. Have told my consultant, that I am willing to participate. It was only through the Plymouth lady, who told me there was a bone marrow unit at Derriford Hospital.

**Q15: Please comment here on any key issues or themes surrounding living with CLL that you think I have overlooked in my list.**

There is a danger of becoming too obsessed with CLL. Regular conference goers made it sound like an exclusive club. The conference locations are so far away, that many West Country people are unable to travel so far. Although a one-off bursary for each year. Up to £125 is available for transport and accomodation. I have requested a conference down here, but places like Middlesex and Leicester are regular venues. They should consider people who cannot travel, because of physical and money restrictions.

<b>#84</b>		<p><b>COMPLETE</b></p> <p><b>Collector:</b> In Our Blood: ...et Use Survey (Web Link)  <b>Started:</b> Sunday, January 06, 2013 3:31:36 PM  <b>Last Modified:</b> Monday, January 07, 2013 7:42:02 PM  <b>Time Spent:</b> Over a day</p>
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PAGE 1: In our Blood

<p><b>Q1: The Project and its Aims</b>As a fellow CLL patient (diagnosed in February 2011), former nurse, and current communications academic, I am interested in the networks of support and information available on the internet. Consuming and sharing information online can transform our experience of illness. From working through the first terrifying stage of diagnosis, to becoming our own advocates, internet communications can play a key role.This doctoral project sets out to explore the way that patients and carers use online networks to make sense of CLL, with the broader aim of improving understanding of what it means to live with chronic blood cancer in the twenty-first century. As far as I am aware, this is the first potential large-scale project researching how people respond to living with CLL, and how they use the internet to make sense of their experiences.Taking PartI am inviting you to answer a few questions about living with CLL, and how you might use the internet to gain information and support with that. The survey is anonymous, secure, and responses can only be accessed by myself as the researcher and account holder. You should allow at least 15 mins to complete the form, depending on the length of your answers. You may partially complete the survey, and return to it later to complete if that is preferable.How the Data will be UsedThe results will be submitted as part of my PhD thesis for University of the Arts London and Falmouth University. Work in progress will be written up for journal articles and conference papers. The project is receiving no external funding. RisksThere is no risk inherent in taking part in this survey. All responses are anonymous and cannot be attributed to any individual. Your IP address will not be stored, and information is encrypted and transmitted over secure channels.BenefitsThe benefits are long-term and are about contributing to improved understanding of what it means to live with CLL.How the Data will be UsedThe results will be submitted as part of my PhD thesis for University of the Arts London and</p>	<p>Yes</p>
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Falmouth University. Work in progress will be written up for journal articles and conference papers. The project is receiving no external funding. If you have any questions please contact me in the first instance at: Julia Kennedy, Senior Lecturer, BA (Hons) Journalism, University College Falmouth, Treliever Road, Penryn, Cornwall, TR10 9EZ julia.kennedy@falmouth.ac.uk You can also find further information about the project, along with hard copies of participant information and consent forms to download if you wish on the research blog <http://julesk-inourblood.blogspot.co.uk/> By clicking yes below, you confirm that you have read this description of the study, are over the age of 18, and that you freely consent to completing the survey and to your responses being used in the project described.

PAGE 2: How I use the internet to gain information about CLL

<p><b>Q2: Please tick any of the online sites below that you use to gain information and support about CLL.</b></p>	<p>CLLCanada, CLL Topics, PubMed, ACOR list, CLL Global</p>
<p><b>Q3: If you use participatory sites (support group, listserv, facebook, YouTube), please indicate your level of participation</b></p>	<p>I post online about CLL issues occasionally, I rarely visit or contribute to CLL sites online, Please use the box to indicate an approximate frequency of your postings 2x per month</p>
<p><b>Q4: If you do post to online sites, please indicate what kind of contributions you make by ticking the relevant boxes below</b></p>	<p>I post when I need advice on a CLL issue</p>
<p><b>Q5: If you don't actively participate in the sites you use, please indicate why that may be.</b></p>	<p><i>Respondent skipped this question</i></p>
<p><b>Q6: Do you feel that your internet use surrounding CLL has made you into a more informed patient?</b></p>	<p>Yes</p>
<p><b>Q7: Do you think that having more information helps you to deal with living with the disease?</b></p>	<p>Yes, Please comment briefly - particularly if you answered "sometimes" Yes, a huge amount!!!!!! Would be quite in the dark without the internet sites.</p>



**Q8: Does being more informed about CLL affect your relationship with your medical team?**

Yes, I discuss what I have learned online with my Doctors.

If you answered "yes" please comment on how your Doctors react to this. If you answered "no", please write a few words explaining why. Have only had one discussion. I think I knew more than my husband's doctor did. Perhaps for that reason, the discussion did not go very far, however the doctor was willing to learn and do what I was asking.

PAGE 4: Living with CLL: The Key Issues

**Q9: Diagnosis is clearly a huge challenge for those of us with CLL to come to terms with. Please make any observations about how you dealt with or are dealing with the challenge of diagnosis. If any particular online resource/s were or remain especially helpful to you, please identify them in your comment. If you were diagnosed prior to ease of access to internet support, please say something about how you gained information and support.**

*Respondent skipped this question*

**Q10: One of the key themes for discussion online around CLL is that of prognosis. Major concerns are expressed around who gets prognostic testing, and the effects of knowing our prognostic markers. Please make any observations about how you have gained information and advice to help you negotiate your own attitudes to CLL prognosis. If any particular online resource/s are especially helpful to you (or otherwise), please identify them in your comment.**

I learned about the prognostic indicators from reading various websites and listening to podcasts and webcasts. Has not helped much yet as my husband has not had FISH or any other testing yet. (he has SLL)

**Q11: Please contribute any observations here about how you have negotiated the challenge of learning to live with CLL. This question is really about how we adjust our lifestyles and attitudes (both emotionally and physically), and what resources we draw on to help with that. Again - if any specific sites, resources or online activities have helped you with that particularly, or if you have used them to share your thoughts about this issue then please identify them in your answer.**

*Respondent skipped this question*

**Q12: Time.** Living with a chronic illnesses can significantly effect a person's sense of control over their own time. This can be about issues such as needing to plan life around hospital appointments, treatment, and fatigue. The approach of "watch and wait" can bring uncertainty to life plans and visions of the future, as can remission length for those in treatment. Say anything you can here about how your own sense of time has been affected by your CLL diagnosis, again referring to any online resources that you have used to help with this where appropriate.

I am in the watch and wait stage stage. My white cell count has stayed about 200 all last year. I look after myself, eat and exercise well. If I want a holiday or to buy something, I tend to do it regardless. Just off to Spain for three weeks, which is a regular January trip for vitamin D.

**Q13: Relationships.** Some people report feeling like "an outsider" following a diagnosis with a serious illness. Use this box to comment on how CLL has made a difference to your relationships with others? What effect does it have on existing relationships with family, friends, and colleagues? Have you decided not to tell other about your CLL for fear of being regarded differently? Have you perhaps built new relationships as a result of your CLL? Please mention any online activities that you have used to work through these issues.

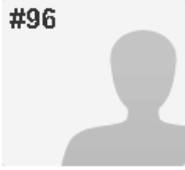
I feel extra sensitive, since being diagnosed. My husband has 3 monthly injections for prostate cancer, so we support each other. Relatives and friends are unaware of the effects of the disease, as it is less common. Long phone chat with a Plymouth lady and we will meet next month. Trying to build up a Devon/Cornwall support group. Only three people from Devon have replied. We need more brochures left out and contact in Cornwall.

**Q14: New treatments and the future.** The CLL world is buzzing at present with news of new treatment protocols and new drug trials in the pipeline. Monoclonal antibodies have enhanced CLL treatment, and the human genome and subsequent cancer genome projects have opened up a "brave new horizons" of approaches to cancer treatments in general, with talk of a "cure" in sight. Please say a little about how these claims affect your attitude to your own CLL, and what online resources you use to keep up with them.

I learnt about drug trials and bone marrow transplants at the Oxford conference. Have told my consultant, that I am willing to participate. It was only through the Plymouth lady, who told me there was a bone marrow unit at Derriford Hospital.

**Q15: Please comment here on any key issues or themes surrounding living with CLL that you think I have overlooked in my list.**

There is a danger of becoming too obsessed with CLL. Regular conference goers made it sound like an exclusive club. The conference locations are so far away, that many West Country people are unable to travel so far. Although a one-off bursary for each year. Up to £125 is available for transport and accomodation. I have requested a conference down here, but places like Middlesex and Leicester are regular venues. They should consider people who cannot travel, because of physical and money restrictions.

<p>#96</p> 	<p><b>COMPLETE</b></p> <p><b>Collector:</b> In Our Blood: ...et Use Survey (Web Link)  <b>Started:</b> Thursday, January 10, 2013 9:29:28 PM  <b>Last Modified:</b> Thursday, January 10, 2013 9:50:15 PM  <b>Time Spent:</b> 00:20:46</p>
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PAGE 1: In our Blood

**Q1: The Project and its Aims** Yes

As a fellow CLL patient (diagnosed in February 2011), former nurse, and current communications academic, I am interested in the networks of support and information available on the internet. Consuming and sharing information online can transform our experience of illness. From working through the first terrifying stage of diagnosis, to becoming our own advocates, internet communications can play a key role. This doctoral project sets out to explore the way that patients and carers use online networks to make sense of CLL, with the broader aim of improving understanding of what it means to live with chronic blood cancer in the twenty-first century. As far as I am aware, this is the first potential large-scale project researching how people respond to living with CLL, and how they use the internet to make sense of their experiences. Taking Part I am inviting you to answer a few questions about living with CLL, and how you might use the internet to gain information and support with that. The survey is anonymous, secure, and responses can only be accessed by myself as the researcher and account holder. You should allow at least 15 mins to complete the form, depending on the length of your answers. You may partially complete the survey, and return to it later to complete if that is preferable. How the Data will be Used The results will be submitted as part of my PhD thesis for University of the Arts London and Falmouth University. Work in progress will be written up for journal articles and conference papers. The project is receiving no external funding. Risks There is no risk inherent in taking part in this survey. All responses are anonymous and cannot be attributed to any individual. Your IP address will not be stored, and information is encrypted and transmitted over secure channels. Benefits The benefits are long-term and are about contributing to improved understanding of what it means to live with CLL. How the Data will be Used The results will be submitted as part of my PhD thesis for University of the Arts London and

Falmouth University. Work in progress will be written up for journal articles and conference papers. The project is receiving no external funding. If you have any questions please contact me in the first instance at: Julia Kennedy, Senior Lecturer, BA (Hons) Journalism, University College Falmouth, Treliever Road, Penryn, Cornwall, TR10 9EZ julia.kennedy@falmouth.ac.uk You can also find further information about the project, along with hard copies of participant information and consent forms to download if you wish on the research blog <http://julesk-inourblood.blogspot.co.uk/> By clicking yes below, you confirm that you have read this description of the study, are over the age of 18, and that you freely consent to completing the survey and to your responses being used in the project described.

PAGE 2: How I use the internet to gain information about CLL

<p><b>Q2: Please tick any of the online sites below that you use to gain information and support about CLL.</b></p>	<p>Facebook Group (please state which one you use in comment box below)</p> <p>,</p> <p>CLLCanada, CLL Topics,</p> <p>Other (please specify)</p> <p><a href="http://www.cllforum.com/">http://www.cllforum.com/</a> Facebook pages are <a href="https://www.facebook.com/groups/CLLSupport/">https://www.facebook.com/groups/CLLSupport/</a> <a href="https://www.facebook.com/groups/supportllc/">https://www.facebook.com/groups/supportllc/</a> and <a href="https://www.facebook.com/groups/2811455536/">https://www.facebook.com/groups/2811455536/</a></p>
<p><b>Q3: If you use participatory sites (support group, listserv, facebook, YouTube), please indicate your level of participation</b></p>	<p>I actively post online about CLL issues regularly (more than six posts annually - please give a rough estimate of posting frequency in box below)</p> <p>,</p> <p>Please use the box to indicate an approximate frequency of your postings during my treatment and just prior to I posted more regularly now I mainly read..</p>
<p><b>Q4: If you do post to online sites, please indicate what kind of contributions you make by ticking the relevant boxes below</b></p>	<p>I post about the physical and psychological impacts of living with CLL</p> <p>,</p> <p>I post when I need advice on a CLL issue</p>
<p><b>Q5: If you don't actively participate in the sites you use, please indicate why that may be.</b></p>	<p><i>Respondent skipped this question</i></p>

<b>Q6: Do you feel that your internet use surrounding CLL has made you into a more informed patient?</b>	Yes
<b>Q7: Do you think that having more information helps you to deal with living with the disease?</b>	Yes
<b>Q8: Does being more informed about CLL affect your relationship with your medical team?</b>	<p>Yes, I discuss what I have learned online with my Doctors.</p> <p>,</p> <p>If you answered "yes" please comment on how your Doctors react to this. If you answered "no", please write a few words explaining why. My Dr is fine as he can answer my concerns if I have any based on my knowledge</p>

PAGE 4: Living with CLL: The Key Issues

<p><b>Q9: Diagnosis is clearly a huge challenge for those of us with CLL to come to terms with. Please make any observations about how you dealt with or are dealing with the challenge of diagnosis. If any particular online resource/s were or remain especially helpful to you, please identify them in your comment. If you were diagnosed prior to ease of access to internet support, please say something about how you gained information and support.</b></p> <p>From my blood results I had figured it was leukemia I had but needed the diagnosis to know which one. I was surprised at the different leukemias there were. The internet helped me understand it was not a death sentence and put my mind at ease somewhat, it also gave me questions that I could ask for my own piece of mind.</p>
<p><b>Q10: One of the key themes for discussion online around CLL is that of prognosis. Major concerns are expressed around who gets prognostic testing, and the effects of knowing our prognostic markers. Please make any observations about how you have gained information and advice to help you negotiate your own attitudes to CLL prognosis. If any particular online resource/s are especially helpful to you (or otherwise), please identify them in your comment.</b></p> <p>I didn't have a fish test or anything and it took me awhile to understand the blood tests and what they were looking for other than the WBC, and understanding it is all the numbers not just wbc but lymph count too etc. I did feel better when my first Onc said I'd probably not need treatment for many years if at all....I was diagnosed in 2006 and had treatment in 2012</p>
<p><b>Q11: Please contribute any observations here about how you have negotiated the challenge of learning to live with CLL. This question is really about how we adjust our lifestyles and attitudes (both emotionally and physically), and what resources we draw on to help with that. Again - if any specific sites, resources or online activities have helped you with that particularly, or if you have used them to share your thoughts about this issue then please identify them in your answer.</b></p> <p>Because fatigue is common in CLL I really didn't notice how bad it had got until the blood tests showed I needed treatment. I had changed how I did things etc to the point I started sleeping on my left side not realizing that it was because my spleen was so enlarged.</p>

**Q12: Time.** Living with a chronic illnesses can significantly effect a person's sense of control over their own time. This can be about issues such as needing to plan life around hospital appointments, treatment, and fatigue. The approach of "watch and wait" can bring uncertainty to life plans and visions of the future, as can remission length for those in treatment. Say anything you can here about how your own sense of time has been affected by your CLL diagnosis, again referring to any online resources that you have used to help with this where appropriate.

see above and also I have continued living my life enjoying children and grandchildren more but this is not because of CLL, my son tragically was murdered in 2009 at 31 and this made me realize we have no control about when we die but what we do while we are here...

**Q13: Relationships.** Some people report feeling like "an outsider" following a diagnosis with a serious illness. Use this box to comment on how CLL has made a difference to your relationships with others? What effect does it have on existing relationships with family, friends, and colleagues? Have you decided not to tell other about your CLL for fear of being regarded differently? Have you perhaps built new relationships as a result of your CLL? Please mention any online activities that you have used to work through these issues.

My husband has been a dream, a person I thought would not be able to handle it has really surprised me and is extremely supportive.

**Q14: New treatments and the future.** The CLL world is buzzing at present with news of new treatment protocols and new drug trials in the pipeline. Monoclonal antibodies have enhanced CLL treatment, and the human genome and subsequent cancer genome projects have opened up a "brave new horizons" of approaches to cancer treatments in general, with talk of a "cure" in sight. Please say a little about how these claims affect your attitude to your own CLL, and what online resources you use to keep up with them.

I am praying my remission lasts until there is a pill a day maintenance similar to insulin for a diabetic...

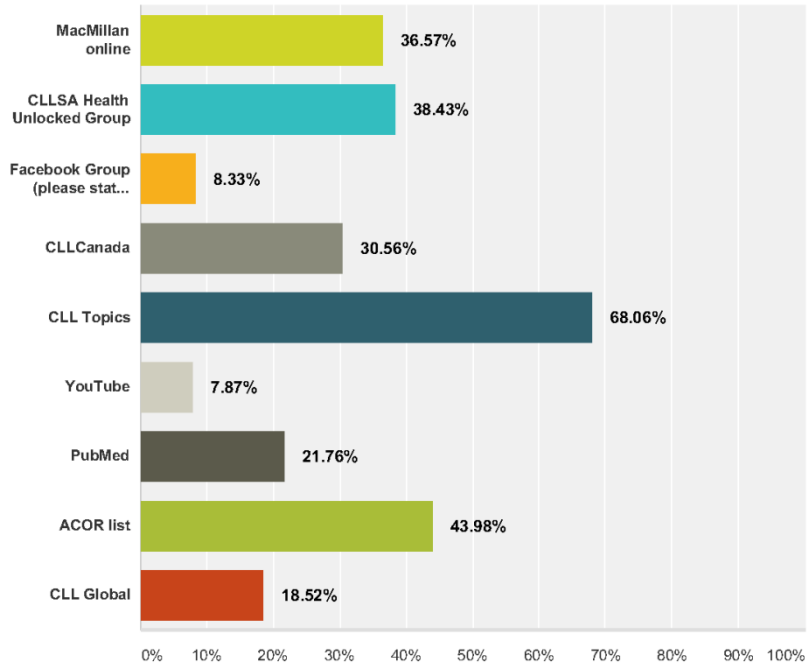
**Q15: Please comment here on any key issues or themes surrounding living with CLL that you think I have overlooked in my list.**

Depression...although with me I couldn't tell you if depression was CLL related or my son's death...Also with night sweats being 50 at diagnosis how can anyone tell menopause from CLL...



**Q2 Please tick any of the online sites below that you use to gain information and support about CLL.**

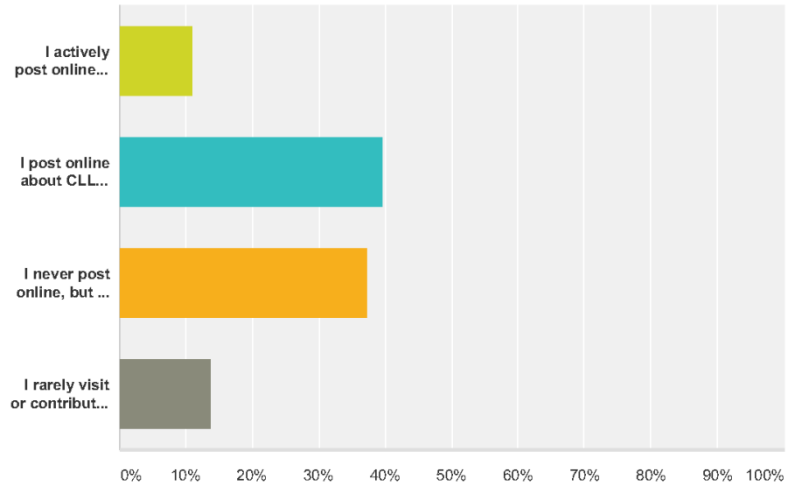
Answered: 216 Skipped: 45



Answer Choices	Responses
MacMillan online	36.57% 79
CLLSA Health Unlocked Group	38.43% 83
Facebook Group (please state which one you use in comment box below)	8.33% 18
CLLCanada	30.56% 66
CLL Topics	68.06% 147
YouTube	7.87% 17
PubMed	21.76% 47
ACOR list	43.98% 95
CLL Global	18.52% 40
<b>Total Respondents: 216</b>	

**Q3 If you use participatory sites (support group, listserv, facebook, YouTube), please indicate your level of participation**

Answered: 217 Skipped: 44

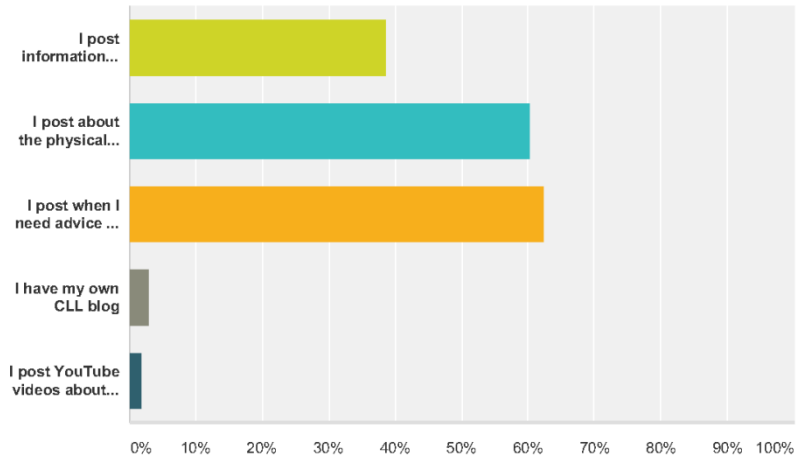


Answer Choices	Responses
I actively post online about CLL issues regularly (more than six posts annually - please give a rough estimate of posting frequency in box below)	11.06% 24
I post online about CLL issues occasionally	39.63% 86
I never post online, but I regularly log into and read one or more CLL sites.	37.33% 81
I rarely visit or contribute to CLL sites online	13.82% 30
<b>Total Respondents: 217</b>	



**Q4 If you do post to online sites, please indicate what kind of contributions you make by ticking the relevant boxes below**

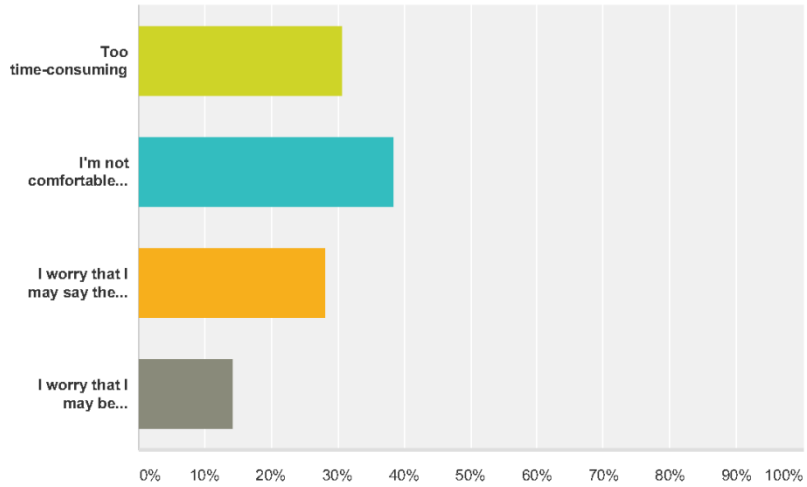
Answered: 101 Skipped: 160



Answer Choices	Responses
I post information about CLL - treatment protocols, research papers that I have found, links to medical information, legal information about employment/insurance etc.	38.61% 39
I post about the physical and psychological impacts of living with CLL	60.40% 61
I post when I need advice on a CLL issue	62.38% 63
I have my own CLL blog	2.97% 3
I post YouTube videos about CLL	1.98% 2
<b>Total Respondents: 101</b>	

**Q5 If you don't actively participate in the sites you use, please indicate why that may be.**

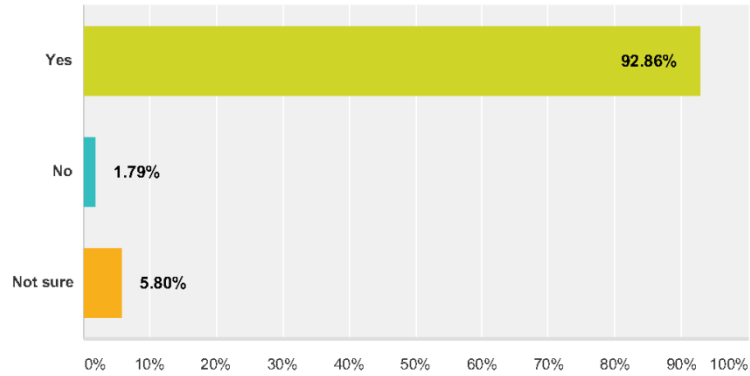
Answered: 78 Skipped: 183



Answer Choices	Responses
Too time-consuming	30.77% 24
I'm not comfortable using online communications for such a sensitive issue	38.46% 30
I worry that I may say the wrong thing or upset others on the site	28.21% 22
I worry that I may be identified from my postings, and that my confidentiality may be threatened	14.10% 11
<b>Total Respondents: 78</b>	

### Q6 Do you feel that your internet use surrounding CLL has made you into a more informed patient?

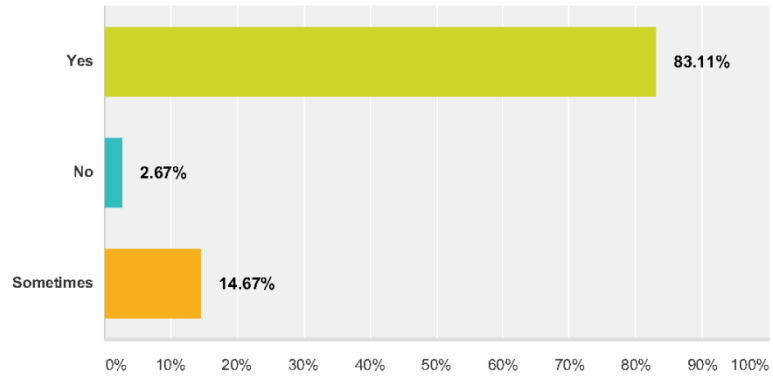
Answered: 224 Skipped: 37



Answer Choices	Responses
Yes	92.86% 208
No	1.79% 4
Not sure	5.80% 13
<b>Total Respondents: 224</b>	

**Q7 Do you think that having more information helps you to deal with living with the disease?**

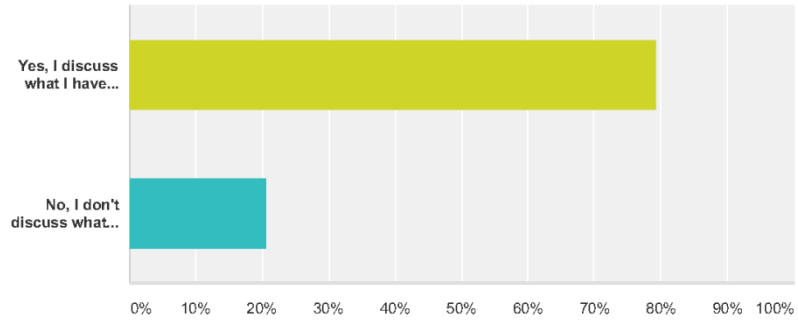
Answered: 225 Skipped: 36



Answer Choices	Responses
Yes	83.11% 187
No	2.67% 6
Sometimes	14.67% 33
<b>Total Respondents: 225</b>	

### Q8 Does being more informed about CLL affect your relationship with your medical team?

Answered: 222 Skipped: 39



Answer Choices	Responses
Yes, I discuss what I have learned online with my Doctors.	79.28% 176
No, I don't discuss what I see online with my Doctors	20.72% 46
<b>Total Respondents: 222</b>	

**Q15 Please comment here on any key issues or themes surrounding living with CLL that you think I have overlooked in my list.**

Answered: 96 Skipped: 165

#	Responses	Date
1	On diagnosis you are always warned not to research on the internet: scary reports; unfounded conclusions; expectations, rogue sites, etc. It would have been so helpful to have been made aware of support and information web sites via a reliable source, rather than fumbling in the dark when you are still shell shocked. Even now I feel I am treading carefully with internet sites as they can appear to be quite anonymous.	4/28/2013 7:30 PM
2	People focus on 'cure' but we will most likely die of infection. The evidence about preventing and managing infections (eg the debate about double flu vaccination) is small and often unknown to clinicians.	4/23/2013 10:04 AM
3	None	4/15/2013 12:44 PM
4	It seems a lot easier to follow what's happening (eg. in clinical trials / new developments) in USA using the internet than it does in UK.	4/10/2013 10:49 AM
5	I can't think of any.	4/9/2013 8:02 PM
6	I think it is very difficult to do this sort of thing as a questionair we are all diferent	4/9/2013 2:33 PM
7	None	4/7/2013 11:15 AM
8	Can't think of any.	4/5/2013 6:29 PM
9	How one made a decision on when and how to tell family and friends	4/5/2013 9:58 AM
10	Keeping positive, keeping in touch with fellow CLL patients where possible, and being careful not to succumb to 'information overload' from the Internet - it can sometimes be quite exhausting!	4/4/2013 10:02 PM
11	Compared to other cancers I feel a fraud.	4/4/2013 3:04 PM
12	When I was initially diagnosed with CLL 9 years ago I became obsessed with finding the right place for my family to have a funeral for me that meant something to them. I stumbled across the Unitarian chapel in York and have become a very active member of this community, as they are not necessarily Christian, as I am not.	4/4/2013 11:50 AM
13	You seem to imply that "online" is the most important contact for CLL patients. I have received ample help from the consultant, the nurses, Macmillan leaflets and nurses, St Luke's Hospice alternative therapies (especially watercolour painting!)	4/4/2013 9:34 AM
14	It is not so much online help but I think there should be more help from the hospitals and them informing us as patients where help can be found	4/4/2013 8:21 AM
15	The main thing that is really bad about dll is the infection problem and the general lack of concern with kids with measles, chickenpox whooping cough, and loads of coughs and sneezes always aimed right into ones face in the street or supermarket	4/3/2013 9:17 PM
16	No not that I can think off.	4/3/2013 8:57 PM
17	I feel you have probably covered all the main issues except how CLL is relevant when other health issues crop up. I have already mentioned my leg problem. Should other health issues be taken more seriously in CLL sufferers (or indeed anyone who has a compromised immune system) and actions taken over them when no action might be taken for people who have a normal immune system?	4/3/2013 7:08 PM
18	You haven't for me - I hope you get on ok. I was diagnosed at WC27. It gradually went up to 270 this year when I started treatment.	4/3/2013 6:16 PM
19	Lack of knowledge of CLL with GPs, I was told CLL was like having a spot of skin cancer.	4/3/2013 3:10 PM

## 'In Our Blood' CLL and Online Use Survey

SurveyMonkey

20	Watch and wait is still a difficulty to understand. Am hoping a support group nearer home might be forthcoming. What symptoms to look out for were not offered by the consultant, and I had to ask specifically, and go on line (google search again!)	4/3/2013 2:08 PM
21	it can seem that blood cancer in older people has not the same impact and therefore not as important people are not so aware that it is a very common cancer	4/3/2013 12:19 PM
22	When first diagnosed the hospital consultant haematologist said " this is the best kind of cancer to get" that really knocked me about - the use of the word CANCER. it took about a year and using the web to realise that it was inappropriate off the cuff remark.	4/3/2013 11:18 AM
23	Many people, like myself, have no hospital support, unlike those who are given a clinical nurse contact on diagnosis. My first point of contact is always my GP who is not well informed about CLL.	4/3/2013 11:01 AM
24	There are no positives. I would not wish anyone to be diagnosed with CLL, but it is not suddenly the end of the world and I believe their should be more made of the positives, it is slow growth in most cases, modern treatments are successful in giving a longer remission time than previously, you can live a reasonable normal lifestyle, I understand there will be some exceptions, but in general it is a condition that can be managed and lived with for the most part. Or perhaps I have just been lucky,	4/3/2013 11:00 AM
25	I think anything that brings information about this condition (which affects a lot more people than most realise) to a wider audience is an excellent theme and I wish you well with your research.	4/3/2013 10:31 AM
26	CLL does not rule my life at all. I ignore it, apart from the obvious lymphadenopathy. I have put it in a pigeon hole. I take it out of that and look at it from time to time, otherwise, I forget it. I am lucky, I know.	4/3/2013 9:56 AM
27	Please take everything that you read or hear on CLL with some scepticism before believing it. I realise that is all reads as profoundly negative, but I am not a negative person neither do i live in a negative way. I do as much as I can for the community, I just got fed up with the loud mouthed idiots.	4/3/2013 9:24 AM
28	I don't really use online resources, mainly because I have such excellent support from the medical teams I am under - I have two teams in different locations due to my participation on the trial. One consultant is the regional specialist in CLL and I have every confidence in them. I can go to them at any time and ask any questions. Therefore, the need to trawl the internet or speak with others is not something I think about at this time. I appreciate others may find comfort in this. My family have occasionally found information on the internet and quite frankly it has not been helpful - either scaring them or getting their hopes up.	4/3/2013 7:54 AM
29	You allude to multiple sources of information, but I suspect many people are just not aware of them. It would be useful to have a central reference of support services (although this may not be within your remit).	4/3/2013 6:26 AM
30	I hope this is of some use to you. I wish you well with your project.	4/3/2013 1:09 AM
31	I hope I have been honest that I do not use online information as I feel it is misleading. Listen to the professionals and have faith in them.	4/2/2013 10:23 PM
32	Perhaps what treatments people may have received, any side effects and outcomes? Length of time since diagnosis to treatment (if treated)?	4/2/2013 9:59 PM
33	I wish there was more information on possible symptoms and related aches and pains because such knowledge would help relieve the mystery concerning our illness. I would also like more information on support gained from nutrition practices, eg are there any that help?	4/1/2013 7:54 PM
34	For me it is not easy as the CLL makes me feel ill or at least I do not have a feeling of wellness. I am speaking about the physical problems. Emotionally I am a stong person.	4/1/2013 5:00 PM
35	Online resources are really excellent and invaluable, but I think the provision of face to face human support, advice, help is lacking certainly in some areas of the coutry and i think a vital provision. I think the provision of other help varies hugely from place to place. I looked online the other day at Maggie's Centres, which appear to set out to fill in the gaps in current provisional, and there are new ones being built around the country. Maybe this is one future source of support too.	4/1/2013 2:45 PM
36	I would say that your list is pretty comprehensive and look forward to reading the results of your study. Good luck!	4/1/2013 10:09 AM
37	The psychological effects of being told you have cancer are not well understood. I have spent some time helping others recently diagnosed with CLL.	3/31/2013 10:18 AM

'In Our Blood' CLL and Online Use Survey

SurveyMonkey

38	My key issue is in wanting to have a better link of communication between myself/GP/Consultant and/or bodies such as DWP/insurance companies etc. Visiting a GP feeling really bad with infection etc, can mean going to the nurse - giving blood sample -making another appointment to see GP.... in the meantime ...no treating of the illness that I went to see the GP with in the first place, DWP ... You're CLL is ' stable - not being treated ' ....What about the symptoms of 'stable' CLL ? .... or how it interacts with my other chronic illnesses ? ...nothing, no 'box' to tick.	3/31/2013 9:04 AM
39	We as members in patient groups should have access through our patient groups, to medical journals, just like college or grad students have access to those journals through their universities. As patients we are frequently much more dedicated in our studies than the average student.	3/9/2013 2:09 AM
40	I would like to supply a list of symptoms and see how they compare with other CLL ers.	3/5/2013 11:31 AM
41	I was only diagnosed about 4 weeks ago, so I am about to face a lot of issues above. Happy to re-do this survey in 6 months after I have faced issues. I am Quarry on Health Unlocked site	2/6/2013 9:32 AM
42	From my participation in various fora I have found many CLL sufferers to be inward looking and preoccupied with their illness and its possible and actual effects. That I find to be a shame as it is a waste of their time and vitality. I am unsure how CLL sufferers can be encouraged to get on with their lives.	1/22/2013 2:22 PM
43	when should we see a specialist in CLL	1/18/2013 9:17 PM
44	I don't remember if you asked whether treatment decisions of patients were affected by what they found on the Internet or with the groups in which they might participate.	1/16/2013 3:54 PM
45	None. My case is a bit different from most because I am 65 with toddler twins, and I still consider my health to be excellent (even with an incurable cancer). I continue to ski, bicycle to work, etc., without any lifestyle limitations. But that is not a shortcoming in your survey; rather it is that I am an outlier.	1/16/2013 6:04 AM
46	Place it where it best fits..... but CLL affects us all so differently, but we are in some kind of club together. Some of the online sites (CLL Digest) allow us to vent, connect, and learn we are not alone. It has been most helpful.	1/12/2013 12:00 AM
47	Natural Strategies.	1/11/2013 1:41 PM
48	1. Cost of treatment in jurisdictions like the United States which operate their health care on a for profit basis. Treatments which you can't afford may as well not exist. As the New World Order continues its war on institutions of collective benefit, like the NHS, it will be less able to handle the demographic tidal wave of over 60's which is on its way. Will the state just let the poor die? This is an important public policy issue. 2. More people are turning to reassuring but useless therapies like homeopathy and naturopathy, in part because they feel listened to, as if their case was important to the practitioner. This is not always the case with conventional medicine which often overlooks the important of "bedside manner" 3. A tax credit for the chronically ill would be nice!	1/11/2013 5:19 AM
49	There are many very frightened people with CLL who do not have the advantages I have of knowledge, good supports, a strong faith and a peace in life. Knowledge is key and getting that info out there is vital. I remember when first diagnosed coming out of a home visit having just helped a stage 4 CLL elderly patient, feeling very shaken. I went online, found the Canadian L&L society, phone numbers etc. -it took about a year of reading, talking attending conferences until it felt incorporated into everyday life. In our city there are monthly meetings- don't attend as driving kids to activities but it's good this is available. Online is okay but having people to talk to with same/similar diagnosis was even more important and shouldn't be neglected. Also meeting/conferences are important.	1/11/2013 1:04 AM
50	There is only one thing that comes to my mind and that is the effect of an enlarging spleen on wardrobe possibilities. I am currently carrying the equivalent of a healthy 5 month pregnancy and now having to hunt for slacks with an elastic waistband and also long shirts to disguise the 'situation' somewhat. Changes in physical appearance and how to cope with them both physically and emotionally is something I don't think you've covered, unless I missed it. I guess it could fit under #11 above, but there I took the reference to physically to mean more along the lines of fatigue and contracting other ailments due to lowered resistance. I just hit the 'next' and realised I am at the end, and came back here to add this. For all the crappy surveys I have done in my day, and even some of the ones I have administered to others when I worked for Statistics Canada, this stands out as the best by far. Each and every question has been well phrased and thoughtfully set out. Well done!! Thank you for your efforts, and I wish you the very best with your own illness and treatment - Grace Nesbitt Fulford, Brantford, Ontario bill.forebears@rogers.com	1/11/2013 12:52 AM
51	Impact on employment.	1/10/2013 11:26 PM



## 'In Our Blood' CLL and Online Use Survey

SurveyMonkey

52	As a UK patient you may not be aware of the potential costs to be incurred by a patient. Since the most advanced drugs are generally not tested in Canada as frequently or as early as they are in the USA, I was fortunate to get my therapy in the USA. Although the trial drug(s) were free, I was responsible for all other expenses. Fortunately I was allowed to have all BMBs, scans, blood work, etc. done in Canada and the clinic accepted the faxed results. I was also able to receive Rituxan free of charge, thanks to the manufacturer and got a discount from both the clinic and my doctor. Although Rituxan was part of the therapy, patients were responsible for the cost of Rituxan, a considerable expense, around \$20,000 per each of infusions. Although I am insured in Canada, hence my BMBs and scans were free to me, the insurance does not cover drug trial expenses, esp. in another country. I was again most fortunate that my Canadian oncologist was able to have all my BMBs etc. covered. A scan and a BMB in the US clinic runs to \$1,400. In sum, for many the lack of insurance and lack of cash prevents them from receiving up to date treatment. As a Canadian I am not able to take out US health insurance.	1/10/2013 10:47 PM
53	Depression...although with me I couldn't tell you if depression was CLL related or my son's death...Also with night sweats being 50 at diagnosis how can anyone tell menopause from CLL...	1/10/2013 9:50 PM
54	Stress seems to be a big issue and it is my belief that psychological counselling is vital in treatment of this disease.	1/10/2013 9:43 PM
55	Excellent survey. Good luck	1/10/2013 11:59 AM
56	The key factor in my living with CLL has been my friendship with my haematologist.	1/9/2013 6:52 PM
57	Hmm, emotional issues?	1/9/2013 5:48 PM
58	I would say that if you are fortunate enough to have a long remission, set a goal to see how many days in a row you can go without thinking about CLL whatever. I had my computer set up to archive the ACOR list without me needing to read it (I didn't read it for six years), and had an online calendar service to send me reminders about getting blood work and check ups with my oncologist twice a year. Now that I'm out of remission mode and possibly facing more treatment, I've become more diligent about keeping up. Nevertheless, I just have to question the whole concept of letting a disease reorder your life any more than absolutely necessary. I say, don't live "with CLL", just live.	1/9/2013 5:26 AM
59	Rising lack of independent life style, mobility, and the like.	1/8/2013 12:40 AM
60	This has been a good survey, and I have appreciated the opportunity it has given me to do some personal reflecting. Best of luck as you continue your study!	1/7/2013 6:53 PM
61	Changes in current lifestyle. Some folks are tempted to 'give up' - and others fight valiantly. Some ignore it, and some spend much time thinking and worrying about it. This approach seriously affects one's lifestyle. Also, the possibility of patients helping patients.....	1/7/2013 1:50 PM
62	N/A	1/7/2013 5:27 AM
63	Nothing that comes to mind...	1/7/2013 3:02 AM
64	Insurance issues, financial concerns, and MAYBE the positives gained from shifting into a realization of our own mortality and how much we are loved.	1/7/2013 2:49 AM
65	In my observations I have noticed many people have questions that relate to the medical uncertainty surrounding CLL. People lost of questions about quality of life especially fatigue. But the answers are only anecdotal because there is very little research on CLL's impact on quality of life of people who have not been treated. From what I have read on the list this is a very important issue. I am pleased to see that someone is doing research on this topic. I am university Professor in a kinesiology department. I have been thinking about doing such a study myself. If you would be interested in discussion your project with me further as a participant or colleague. I can be reached via e-mail at placebo_09@yahoo.ca	1/7/2013 12:06 AM
66	{(1) How CLL is different from other cancers, (2) How some people don't take CLL as a serious cancer (eg, oh, you only have CLL ...)	1/7/2013 12:05 AM
67	I would wonder about how people actually think of their disease. I hear all the time on the list about beating "the dragon" as if CLL is some evil force in their lives. I know that it is cancer, but after all it is only my own blood cells misbehaving (as all cancers are) so I don't think of it as an enemy. My body so far has been dealing with these cells, and as long as they don't cause any trouble I don't mind them being around. I would think that if I thought it was a "dragon" out to get me it would make me feel more victimized. But others seem to like to feel that they are conquering a beast. I find that interesting.	1/6/2013 9:55 PM

'In Our Blood' CLL and Online Use Survey

SurveyMonkey

68	Care in exposure to germs....especially during flu season. Worry about being infected by grandkids hugging and kissing etc. People thinking you are too normal and you feel uncomfortable when you are cautious or eat organic food and drink filtered water....	1/6/2013 9:46 PM
69	finding the right doctors	1/6/2013 9:04 PM
70	I think that the most important piece of information I have learned from ACOR is that you must see a CLL specialist before making any plans for handling the disease. My regular CLL oncologist is an excellent doctor practicing at a highly regarded teaching hospital. That said, I have learned things from the ACOR list that she was not aware of. You must be your own advocate.	1/6/2013 7:15 PM
71	You have covered the waterfront.	1/6/2013 5:50 PM
72	Do your homework and see a specialist - even if it means traveling miles from home, even if it means offending your initial oncologist.	1/6/2013 5:12 PM
73	It is important not to become a cancer patient in terms of how we think about ourselves. We are people first and patients second, third or forth. I am a dad, a retired person, a friend, brother and somewhere down the line, a cancer patient. One side effect of CLL is that I have met some wonderful people. Best to you!	1/6/2013 4:52 PM
74	I, for one, think I'm in good medical hands, and have a number of local options when & if treatment is needed. I think others struggle more with finding the right doctors.	1/6/2013 4:46 PM
75	This is a wonderful survey, thank you.	1/6/2013 4:18 PM
76	Thank GOD for the internet...has given peice of mind, and points of view would not have been able to comprehend without it..	1/6/2013 4:14 PM
77	Cost. The cost of treatment here in the U.S. is outrageous and could plummet not only our savings but our home ownership as well.	1/6/2013 3:20 PM
78	I think you've covered things brilliantly.Thankyou for the opportunity to put down my thoughts	1/6/2013 2:39 PM
79	I'm lucky to live in a hotbed of cutting-edge medical care. People in the US without good insurance coverage or living far away from such areas can be "up the creek"	1/6/2013 12:37 PM
80	Being on W&W for over 10 years means just noting that there is a disease and just getting on with life in as normal a manner as possible. I wonder of others on W&W do amend their lifestyle or attitude to living in the longer term. I note that the majority of those who comment on CLL Digest seem to have more acute forms of the disease. There may be some bias in the selecting of people's comments with few with the long-term W&W situation.	1/6/2013 11:59 AM
81	In the US there is a huge issue of health insurance. Just when you are too sick to work is when you need the insurance, but if you stop working you have to pay enormous amounts for it. And if you stop working you don't have money to pay for it. This is just plain wrong! In other countries the issue might be how to be able to get treatments that are not approved for their systems. I think I worry more about insurance than I do about being sick. Even Medicare, our old-age benefits, covers only 80%, and 20% of a very large number is still going to bankrupt me.	1/6/2013 8:21 AM
82	The importance of seeing an expert in CLL. Also being aware of the likelihood of the experts having a bias toward using the protocols that they are researching, a sad sideline to seeing an expert. It gives reason to be educated oneself. Important to have a partner also being educated as it is so complicated, need to share info with someone, need an advocate.	1/6/2013 6:19 AM
83	Sorry if I sent this twice. I somehow deleted one so my responses.	1/6/2013 5:36 AM
84	If you don't like your Dr. - move on to another one and at the very least, get a second opinion. You probably aren't getting too many responses due to age of many of the people getting CLL and the younger ones may not want to take the time.	1/6/2013 5:11 AM
85	Not sure you explored the fear we feel when the word blood cancer or leukemia is first mentioned. That initial wait from time one is told to see an oncologist to the time one receives the actual diagnosis and prognosis. I started reading all sorts of things on line that got me even more worried. That was the most agonizing time- the not really knowing just what was wrong.	1/6/2013 4:08 AM
86	You might want to look into secondary cancers as a result of first line treatments for cll.	1/6/2013 3:46 AM
87	One's personality has a big bearing on all the questions you've asked. I don't know how that would relate to your research, but it might be an angle you could pursue. Some people are more optimistic than others, and I assume they cope better with W&W and relationships than pessimistic people.	1/6/2013 3:27 AM

## 'In Our Blood' CLL and Online Use Survey

SurveyMonkey

88	I am very glad that you are doing this. I think the survey is thoughtful and quite complete. Many thanks for your work.	1/5/2013 10:30 PM
89	Clinical depression is a very real issue with some CLL patients, and is just as likely for those in Watch and Wait as for those facing treatment, and can hit at any time logical or not. I feel that most doctors do not understand, and discount, issues like depression, fatigue, chemo brain, living with night sweats, the personal image issue of visible enlarged nodes, etc. They look at labs and scans, but don't see beyond them to what this disease does to one's psyche. I also think that caregivers are the most overlooked group in cancer communities. Their issues are very different from those of a patient, but there are very few places that offer them support.	1/5/2013 8:27 AM
90	I have not really mentioned on line resources. However the internet is a constant part of my life both personally and professionally. I use search engines every day for all manner of things including CLL. I will visit all and any sites that offer information and then hopefully distill out of them what I need. I use this information as a basis to converse sensibly with my specialists and doctors. These are sites I have bookmarked: <a href="http://clltopics.org/index.php">http://clltopics.org/index.php</a> <a href="http://www.lymphomas.org.uk/information-and-support">http://www.lymphomas.org.uk/information-and-support</a> <a href="http://leukaemialymphomaresearch.org.uk/">http://leukaemialymphomaresearch.org.uk/</a> <a href="http://www.cllfaq.info/index.html">http://www.cllfaq.info/index.html</a> <a href="http://www.cllsupport.org.uk/index.htm">http://www.cllsupport.org.uk/index.htm</a> <a href="http://www.cancerresearchuk.org/cancer-help/type/cll/">http://www.cancerresearchuk.org/cancer-help/type/cll/</a>	1/4/2013 11:35 AM
91	There is a host of smaller matters that surface frequently in CLL discussion, such as safety of certain vaccines and finding CLL specialists when local doctors are clueless. I suspect there is a list of 50 or more such topics, each becoming a "concern" at any given time among CLL'ers. You certainly hit the big issues: first experiences with CLL, adjusting over time to CLL, learning more about CLL as we "mature" with the disease, finding online outlets for our questions and concerns, and becoming both a "lurker" as well as an active participant in online communities. Good Job! and good luck! Hopefully you will share your findings and your interpretations with online support groups like the ACOR-CLL list.	1/3/2013 11:20 PM
92	Perhaps patient attitudes and their experience of clinical attitudes toward complimentary therapies may be worthy of further investigation.	1/3/2013 10:01 PM
93	I personally have a feeling of guilt due to at present feeling very well although I have this illness, maybe an area about how people deal with this.	1/3/2013 9:10 PM
94	Please do not underestimate the amount of support I get from the CLL forum, just to know I am not the only one going through what I am and feeling as I am is wonderful. It has also confirmed my thoughts that medical professionals have poo poo'd especially on fatigue. It is also wonderful to share thoughts on subjects like how to deal with infectious visitors.	1/3/2013 7:32 PM
95	Good coverage. I'd suggest you should include more emphasis on the immune compromises implicit in having CLL - both during its progression and the impact on immunity from chemotherapy and bone marrow transplant treatments. I'd also consider a question investigating the level of involvement we can have in directing more support services and research to improve the quality and length of life for those with CLL.	1/3/2013 1:58 AM
96	There is a danger of becoming too obsessed with CLL. Regular conference goers made it sound like an exclusive club. The conference locations are so far away, that many West Country people are unable to travel so far. Although a one-off bursary for each year. Up to £125 is available for transport and accommodation. I have requested a conference down here, but places like Middlesex and Leicester are regular venues. They should consider people who cannot travel, because of physical and money restrictions.	1/2/2013 9:05 PM

## **Appendix 9: Initial Response to Ethics Committee recommendations**

**(February, 2012)**

Response to Research Ethics Sub-Committee decision on Application for research ethics approval

Julia Kennedy – paper 7/11-12 (my responses represented below committee recommendations, in bold, italicized script)

*In the Blood: Narrative and Rhetoric in online communications of patients with blood cancers*

8.2.2 Following the discussion of the proposal the Committee had the following comments:

- i. The application needs to make clear which organisations are running the websites and online communities being used in the research and the applicant should confirm that she will be complying with their terms of use. If any sites are being run by the NHS then the applicant would also need to comply with the NHS' research ethics procedures.

***It is my intention to focus on Macmillan's online community if possible. I have contacted Macmillan's head office and the local online administrator of the specific community I would like to research. I have been given an in principle approval, and am awaiting a formal response. If this proves difficult or not possible, I will re-focus onto the global ACOR listserv community (although this would not be my preference as I want to look at UK activity specifically if possible).***

- ii. In question 7 of the Ethics application form the student should clarify how she will ensure that the participants (who are self-nominating) will not be children or vulnerable adults.

*In as far as any researcher conducting research other than in face to face contexts can be sure that respondents are who they say they are (i.e. not masquerading as eligible participants when they are in fact not), I consider that the following filters (naturally occurring or imposed by myself) will reinforce the probability of eligibility in respondents.*

*Firstly, the specific chronic blood cancers that I am researching are not childhood diseases. The average age at diagnosis is 55-60. The stated ages in the biographical details offered by members of the community I wish to research are between early forties to late eighties. In that sense, I feel this community is self-regulating in terms of excluding children. Even in cases where a child of a parent with CLL has posted to the community for advice, they have been adults in their own right. Members of the community have to sign up and create a user name and password before posting. No new members post without an introduction to other community members, so biographical detail, including age is offered as part of the introduction, and integration process.*

*In terms of the likelihood of respondents being vulnerable adults, arguably Macmillan's co-operation with my research plans might make what could be considered as members of a vulnerable social group feel coerced into co-operation. I will make sure that all group members are contacted with clear and concise details of the project, its aims, and the ways in which their postings may be used should they give their consent. It will be made very clear that anyone who does not wish to participate will not have their*

***contributions used for the purposes of the research project. Consent will be seen as a dynamic and ongoing process, with frequent updates to include new members, and final consent individually requested before including any postings in the finished PhD document, or any work published as part of the research process.***

***Due to the highly textual and self-motivated nature of exchanges being researched, it is not anticipated that any of the respondents will be adults considered incompetent to consent to research.***

- iii. Section 12 should be removed from the Professional Carers participant information sheet and section 11 from the Online Community Members participant information sheet.

***I have removed section 12 (reward) from professional carers participant form.***

***I have removed section 11 (reward) from online community members participant form.***

- iv. The consent form needs to be more concise.

***I have edited consent forms for both professionals and online community members to contain only that information which is relevant to making informed consent***

- v. The participant consent forms should be adapted for different audiences and further consideration is required on how consent will be given and recorded in an online context where signing a consent form is likely to be impractical

*Since submitting the RF3, the project focus has sharpened to an ethnographic study of a specific community – the Macmillan online community. The online community member participant consent has been adapted to suit that audience. It would also suit any other dedicated online support community for people with chronic blood cancers.*

*Professional carer input, if solicited at all, is likely to be a minor part of this ethnographic project (see point vi below). However, I have revised the form, although it is not yet possible to adapt to a specific professional role until that part of the research process is reached. Therefore I have left a range of possible roles in situ on the form, but would adapt accordingly should this element of the research take place in future. The generic wording of the document would remain appropriate to all professional roles in my opinion.*

*As far as giving and recording consent in an online context is concerned, this is acknowledged to be a major obstacle for online researchers. My sample group is likely to be relatively small. The cancers I am looking at are relatively rare, and the group I propose to look at is at present a small group in terms of membership. If hard copies of signed consent forms are considered essential by the chair, I can mail consent forms to home addresses if participants are willing to provide these, with a stamped addressed envelope for return to myself. Alternatively, I could send forms as attachments to participants e-mail addresses for signing, scanning and returning electronically.*

*I appreciate that the validity of e-mail consent in comparison to a signature is a contested area. However, if the chair agrees to an e-mail confirmation from respondents of receipt, understanding and accordance with the information provided and consent*

*required, this would probably be the most practical approach. The community I plan to research has the facility to follow individual members as friends (if they choose to accept a friendship request) and to message those members privately. This facility allows me to contact group members on an ongoing basis and to exchange information in a private domain. Mann and Stewart (2000) suggest this as a possible solution to the issue of consent in online research.*

*Also underpinned by Mann and Stewart (2000) is the suggestion of setting up a separate site outlining the research aims, objectives, and design. I intend to create a site with a section for FAQs and a short video explaining each stage of the consent process. All potential respondents would be directed to the site with the initial e-mail communication. A comment section would allow for participants to check out information, and they are all able to contact me privately anyway through the community. It would also be possible to create a downloadable consent form accessible from the site which could then be posted back to me if e-mail consent alone is not considered adequate for the project.*

- vi Further information is required on the role that medical staff would play in the research.

*As stated above, the research has focused more intensely on a narrative ethnographic study of the online community itself. The membership of community I propose to look at is largely constituted of people with chronic cancers, rather than carers. However, it may be that I wish to draw on the perspectives of professional carers, such*



*as representatives of Macmillan, CLL specialists, or specialist nurse practitioners to contextualize the work at a later point. Should that be the case, I would be interested in soliciting general opinion about the use and benefits of online support communities by the people with chronic blood cancers in their care. It is by no means a given that this element of the work will be necessary to achieving my research aims. However, I decided to include it at this stage to obviate the necessity of re-applying for consent should I wish to pursue this possibility at a later stage.*

- vii The applicant needs to reconsider the way in which she presents her research to ensure that it was not coercive towards participants and only provided factual information about the project. In particular, the applicant should consider the effects of disclosing her own circumstances on this matter.

*Part of my methodology is to include an element of auto-ethnographic engagement. I am researching online communities of people with blood cancers as a native researcher, and this is intrinsic to the research process. As such, my own status as a person with CLL cannot be concealed within the current project design. Prospective participants in my proposed research community are already aware of my status as a fellow group members with a chronic blood cancer, and my status as an academic and researcher (though not yet of my intention to research within this specific community). My membership of this community is of real value and importance to me, and I deeply value the friendships and associations I have made in the community. It is in my interests to collaborate with the community, subject to their informed consent, in a way that protects and sustains those relationships of trust in a freely consensual and non-coercive*

*context. The spirit of this research as a collaborative endeavour within an already established group of which I am an active member is fundamental to achieving my aims, and will be communicated at all times within the research site.*

*Following Sharf (1999), I would make concerted efforts to contact by e-mail all individuals whose quotes I want to use for published material arising from the research, personally requesting consent to use them. As part of this process, I would remain open to feedback from participants on my interpretation of their quotes.*

*If at any point it is felt that my position as a native researcher, and Macmillan's co-operation with my research presence within the community renders the environment of non-coercive consent and collaboration unworkable, I will re-focus my aims and site of study accordingly.*

*It is possible that I could omit my circumstances from information sent to professional carers (with the exception of Macmillan representatives) should I pursue that element of the research process in due course.*

## References

Mann C., and Stewart, F, (2000) *Internet Communication and Qualitative Research: a handbook for researching online*, Thousand Oaks, Sage.

Sharf, B. (1997) 'Communicating Breast Cancer On-Line: Support and Empowerment on the Internet', *Woman and Health*, 26 (1), pp 65-84.

## **Appendix 10: Extract from the minutes of the Research Ethics Sub-Committee's consideration of my revised research ethics application**

### **Confidential**

#### **RESEARCH ETHICS SUB-COMMITTEE**

Extract from the minutes of the Research Ethics Sub-Committee's consideration of your revised research ethics application submitted in response to the Committee's comments made at their meeting on 21<sup>st</sup> February 2012

**Julia Kennedy (University College Falmouth)**

#### **8. APPLICATIONS FOR RESEARCH ETHICS APPROVAL**

##### **8.2 Student – (Julia Kennedy) Paper 7/11-12**

*In the Blood: Narrative and Rhetoric in online communications of patients with blood cancers.*

**8.2.4 Received:** Julia Kennedy's revised ethics application.

**8.2.5 Agreed:** The Committee were impressed with the thoroughness with which the applicant had addressed the ethical issues relating to her research and also with the thought and effort that had gone into her response to the Committee's comments.

**8.2.6** Following the discussion of the proposal the Committee had the following comments:

- i. The correct contact details for the Research Management & Administration Office should be given on the participant consent form.
- ii. The 'thank you' paragraph in the participant consent form should be removed.

Julia Kennedy

iii. The phrase 'Please take a moment to complete the enclosed survey and return it to me' in the 'invitation' section of the information sheet for Professionals should be changed to: 'Please consider whether or not to respond to the enclosed survey and if yes, please complete it and return it to me'.

iv. A suggestion that the applicant incorporates a full ethics section into her PhD or produces a journal article on this topic, as her discussion and resolutions seem to advance the field rather than merely comply with it.

8.2.7 Agreed: The student is required to make the amendments detailed in points 8.2.6i-iii for consideration by her Director of Studies. Once approved by the Director of Studies, the Committee Secretary should be informed and sent a copy of the approved application. Point 8.2.6iv was offered as a recommendation for the student.

**Appendix 11: Key additional sites used by In Our Blood Survey respondents and a narrative overview of key sites/analytics observed through early fieldwork**

<b>SITE</b>	<b>RESPONSES</b>
<b>CLLSA UK (original site)</b>	<b>11</b>
<b>Bad to the Bone FB page</b>	<b>9</b>
<b>Blogs (Dr. Sharman – CLL Specialist; Dr, Brian Koffman</b>	
- <b>Family Doctor and CLL patient; Dr Terry Hamblin</b>	
- <b>CLL specialist (deceased date); David Arensen</b>	
- <b>CLL patient (deceased date)</b>	<b>8</b>
<b>Cancer Research UK</b>	<b>6</b>
<b>Patient Power (Andrew Schorr)</b>	<b>6</b>
<b>Other FB pages</b>	
<b>(inc. cll watch and wait warriors/BTK inhibitor group)</b>	<b>5</b>
<b><u><a href="http://cllforum.com/">http://cllforum.com/</a></u></b>	<b>5</b>
<b>Yahoo CLL/SLL groups</b>	<b>4</b>
<b><u><a href="http://www.ukcllforum.org/">www.ukcllforum.org/</a></u></b>	<b>4</b>
<b>Leukaemia and Lymphoma Research</b>	<b>3</b>

The following sites also received either one or two mentions across the 77 responses:

**ASH (American Society of Haematology)**

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**Leukemia Lighthouse Connection (FB group)**

**Cancer journals**

**CII Christian Friends**

**[www.leukaemiacare.org.uk/](http://www.leukaemiacare.org.uk/)**

**Generic Google search**

**NHS patient info**

**Mayo Clinic**

**ITP support ass. UK**

**<http://lymphomasurvival.com/>**

**Leukemia and Lymphoma Soc. Of Alberta/Canada**

**<http://www.lymphomation.org/>**

**Wikipedia**

**National Cancer Institute**

**Kimball's Biology Pages**

**Maggies UK**

**Pubmed**

**Medscape**

**Medical conference proceedings/research papers**

## **CLL Sites Online – a narrative overview of some key sites and analytics taken early in the research project (March, 2013)**

As suggested in the introduction, CLL patients have a particularly active online presence. The chronic progressive nature of the disease potentially gives people more time to deeply research their condition and potential treatments, and to set up and maintain long-term online associations in support groups than those facing the immediate need for clinical intervention associated with more acute conditions. The impact of the internet on health communications and knowledge exchange generally will be explored in the following section, but it is clear that information and support provided in the clinical setting is now just one of a range of ways in which many computer literate CLL patients come to understand the bigger pictures of their disease. This overview provides a quick snapshot of CLL networks currently operating online in the UK and US, identifying the major sites, and their current membership or traffic as of March, 2013.

Acor.org, the association of cancer online resources operates as a listserv with membership-only mailing lists covering a range of 170 cancer types. The global CLL list registers 2683 subscribers, with dedicated sub-lists for Canada and the UK recording memberships of 138 and 115 respectively (although it is likely that these people are also members of the global list). Interestingly, the only group currently showing a slightly higher membership of 2866 subscribers is the Myeloproliferative Neoplasm Support group. This is also a haematological malignancy, characterized in this case by excessive production of blood cells, again usually

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diagnosed in older patients and demonstrating a chronic, but incurable progression trajectory similar to that of CLL. The third highest membership is registered by the carcinoid cancer support group with 1399 members. Again, this group of slow growing neuro-endocrine tumours present with indolent, chronic progression. This supports my own observations about the highly active online presence of CLL patients as correlative to the chronic nature of the disease, and fits the profile of the conclusions of the 2010 Pew Internet Research team surrounding the significance of online information in relation to treatment decisions for those with chronic illness (Fox, S., and Purcell, K., 2010).

The Yahoo CLL and SLL (small lymphocytic leukemia) Listserv Group currently registers 989 members, and the Yahoo CLL-Research and Advocacy group currently stands at 651 members.

The two major UK-based groups configure as follows as at March, 2013. The Macmillan CLL/SLL group registers 160 members. The CLLSA UK site set up on the Health Unlocked platform in 2012 registers 306 members.

Non-membership support and information sites such as CLL Topics, CLL Canada, and the CLLGlobal Research Foundation are important nodes in the network. Traffic for CLL Canada can't currently be tracked online, but web analytics site Alexa currently registers 17 sites recording inward links to the site. Traffic to CLL topics was ranked at 2,238,090 globally (461,720 in the US) by Alexa, with a total of 112 sites linking in as at March, 2012. The CLLGlobal Research Foundation is ranked 7,629,257 in the world by Alexa, with 33 sites linking



in. Journalist and CLL patient, Andrew Schorr's site Patient Power has a well-established global CLL advocacy role, alongside growing provision for a range of other diseases. Both CLLGlobal and Patient Power regularly make and disseminate short video interviews with global CLL experts covering current issues in disease research and management, and common questions asked by those living with the disease.

Dedicated, membership-only Facebook group, 'Bad to the Bone: Living with Chronic Lymphocytic Leukemia', registers 316 members as at March, 2013. In addition, there is a significant network of individual and small group CLL websites, blogs, and user-generated videos on YouTube. Several of the larger institutions, particularly those in the US such as the Mayo Clinic, have their own dedicated information pages for CLL patients. There is also a wealth of haematological information for medical professionals, and a rich databank of research papers, and online journals pertaining to the disease. Many of the support sites compile lists of journals and research papers, and link out to them for easy access.

## Appendix 12: Network map and analysis of discussion from Dr Stephen Rosen's video 'An Experts Perspective on Advancing Treatment Progress for Blood Cancers'

Posted to Andrew Schorr's Patient Power advocacy site on 7th January, 2013.

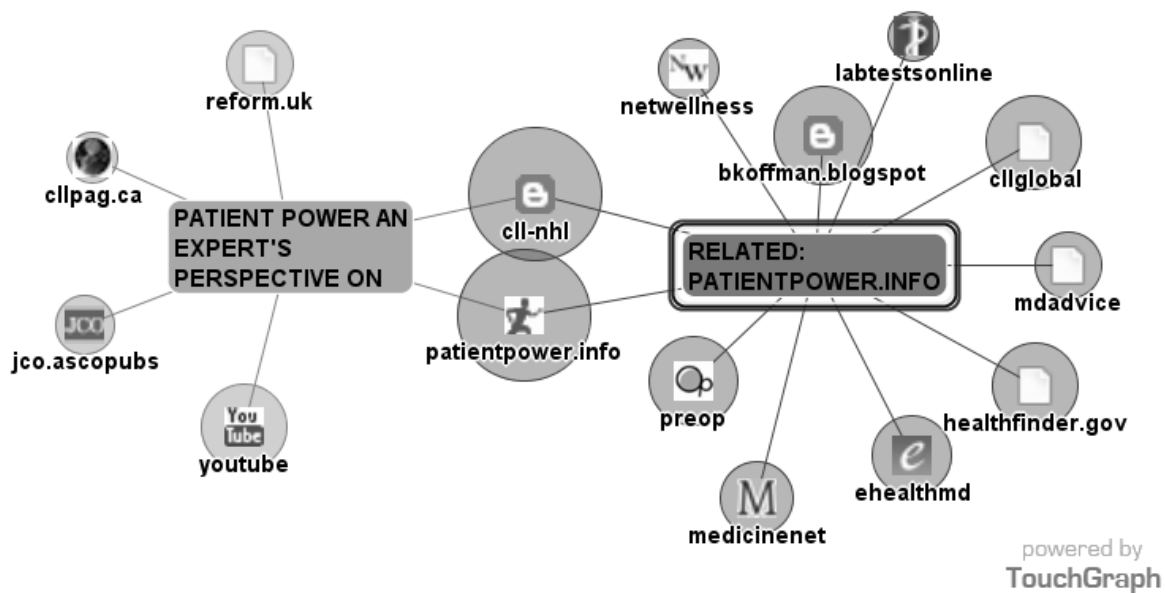


Figure 43: TOUCHGRAPH (2013) Network connections for Stephen Rosen's video 'An Expert's Perspective...' [Network Map]. [Online] Available at: [www.touchgraph.com](http://www.touchgraph.com) [Accessed 03/01/2014].

The video is prefaced with the following introduction:

Dr. Steven Rosen, from the Robert H. Lurie Comprehensive Cancer Center of Northwestern University in Chicago, expresses his excitement about advancements in

blood cancer treatments presented at the 2012 American Society of Hematology annual meeting. Dr. Rosen explains one of the key factors for determining the best treatment course is understanding the genetics of each individual's cancer. As survivorship increases, the paradigm of care is shifting to focus on long term disease management and maintaining quality of life. (Patient Power, 2013)

Combining his skills as a journalist, with his knowledge and experience as a CLL patient, Andrew Schorr leads Dr. Rosen through a number of questions aimed at educating a patient audience. Kicking off with the very current issue of personalized treatment, Schorr raises the question of the role of individual cytogenetics in making treatment decisions. Dr. Rosen responds that the ability to target treatments to the unique biological features of an individual's tumour allows for tailored therapies, and "hopefully by putting together this cocktail of targeted agents you can induce very significant response and remission with very good quality of life (Rosen, cited in Patient Power, 2013).

Rosen then responds to Schorr's question about the new small molecule oral agents, "pills that people can take to control their cancer" (Schorr, cited in Patient Power, 2013). Listing the pros and cons of the small molecules, on the positive side Rosen cites ease of administration, obviating the necessity to come into clinic for treatment, and the rigorous testing process they go through prior to licensing. More problematic in his view is the potential for non-compliance in long-term daily oral drug regimes, (particularly when patients begin to perceive themselves as well after a period of effective treatment), and what he describes as "some unfortunate economic considerations related to oral medications" (*ibid*). This American video naturally presents a US- focused economic perspective. Insurance costs are the issue here, rather than whether or not Health Authorities such as those in the UK and other countries with state run

health care systems can afford, or are willing to prescribe such expensive drugs. However, whatever their geographical location, financial considerations will ultimately apply to all CLL patients in relation to access to treatments, and the issues of managing survivorship highlighted in the comment from Rosen below will play out in a contested economic arena:

...the very practical issues of how you live with an illness for 10, 20 years in some instances on constant therapy but with good quality of life, how do you balance the treatment of your disease with all the other important things that you want to accomplish and all the unique relationships that you have. (*ibid*)

There is very real possibility that a patient will be cared for by one key clinician over the course of many years, so the clinical relationship itself becomes one of the 'unique relationships' that Rosen refers to. Schorr turns at this point in the interview to the question of how that might impact on the nature of patient-clinician relations, suggesting that "open communication" and a sense of "partnership" (*ibid*) are important aspects in long-term clinical relationships. Patient Power is a patient advocacy site and, as such, is concerned with encouraging patients to get the most out of their relationships with those responsible for delivering their care. It is perhaps not surprising then that the audience of this video is encouraged to consider the changing nature of clinical relationships in a new era of cancer treatments. Many points are raised in the networks concerning long-term treatment regimes, predominately issues of economy, access, compliance, long-term efficacy, and physical side-effects. Rarely however is the impact of evolving approaches to treatment and care on the clinical relationship itself directly addressed. Dr. Rosen implies that lifelong partnership with patients and their families lead to holistic

involvement, and increased job satisfaction:

You become very close to your patients. You become part of each other's families. The patient has to feel comfortable they can call on you at any time if they have an issue. The issue doesn't necessarily have to be directly relevant to the cancer itself but relevant to their health that you can help with, and it's what makes oncology the most rewarding field in medicine. (*ibid*)

This doesn't necessarily chime with some of the less engaged clinical relationships reported by patients in this thesis, nor with some of the observations made by clinicians themselves about time constraints in over-stretched clinical settings. Dr. Rosen is a global CLL expert working out of a globally recognized treatment centre. Perhaps it only the 10% of patients suggested by Jeff Sharman (2012) being treated by specialists that can be guaranteed this kind of care, with the other 90% taking their chances among more generalist and pressured regional clinicians. This an important issue indeed as models of all forms of cancer survivorship evolve into potentially much longer periods of ongoing treatment and care for potentially much better informed and engaged patients. The issues Dr. Rosen and Andrew Schorr raise here are of fundamental importance in laying out blueprints for changing clinical relationships for the audience of this video. This is a debate that would usefully incorporate a broader range of clinical voices and experiences, although it is likely that the majority of the Patient Power audience would be patients.

Winding the interview down, Schorr asks Dr. Rosen if he is "encouraged about where we're headed, where we are now?" Rosen's reply that the fields are evolving so quickly that "you can

provide hope for just about every individual you see even at the different stages of the disease” (*ibid* ), again gives the patient audience the sense that, whatever their CLL subset or situation, they are part of this universal hope. Although with very different stakes on the table (job satisfaction versus survival and longevity), in expressing regret that he is not “20 years younger to take advantage of everything that’s going on and to see how it will evolve in the next few decades” (*ibid*), Rosen shows how the horizons of doctors and patients might be fused in a desire to be part of this future.

Building on this perhaps, Schorr concludes the interview with a return to the all-important issue of patient advocacy in the context of pro-active selection of an appropriate clinician when he states that “It would seem that there is some responsibility for patients now to get educated and to seek out a specialist such as yourself so the best care is brought to bear for them” (*ibid*). Dr. Rosen’s reply that this is fundamentally important and that “...you need to be in the hands of experts who treat those diseases, who have an understanding of how to sequence the treatments, how to control the side effects and how to maximize the potential for cure or control of the disease and minimize side effects” (*ibid*) may seem more suited to a US audience for whom the choice of clinician is part of a more generalized consumerist approach to health care decisions. However, and as this work has already shown, choice – where it is available - can be restricted by a number of contingencies such as geography and wellness. It is clearly also the case that some patients outside the US also change doctors when their knowledge leads them to conclude that they could access better care elsewhere. Again, this is dependent on access to information, and the wealth, time and capacity to travel to see a specialist.

### Appendix 13: Summary of the NICE STA process

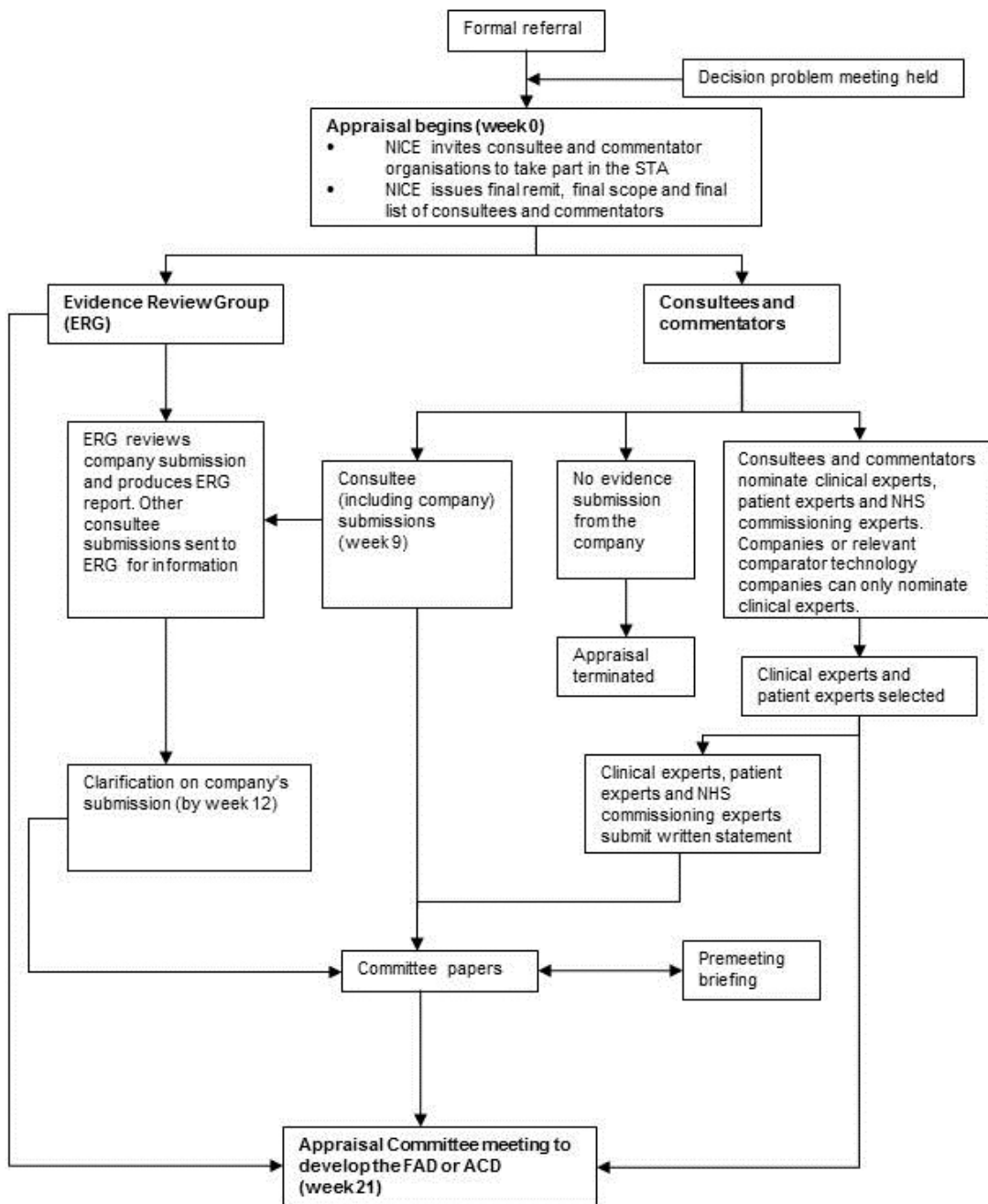


Figure 44: NICE (2014) 'Figure 3 - Summary of the STA process'. NICE 'Guide to the Process of Technology Appraisal', 2014 [Table]. [Online] Available at: <https://www.nice.org.uk/article/pmg19/chapter/3-The-appraisal-process> [Accessed 03/08/2015].

## Appendix 14: Advocacy for Access in the networks - It's Okay (Essential) to Ask

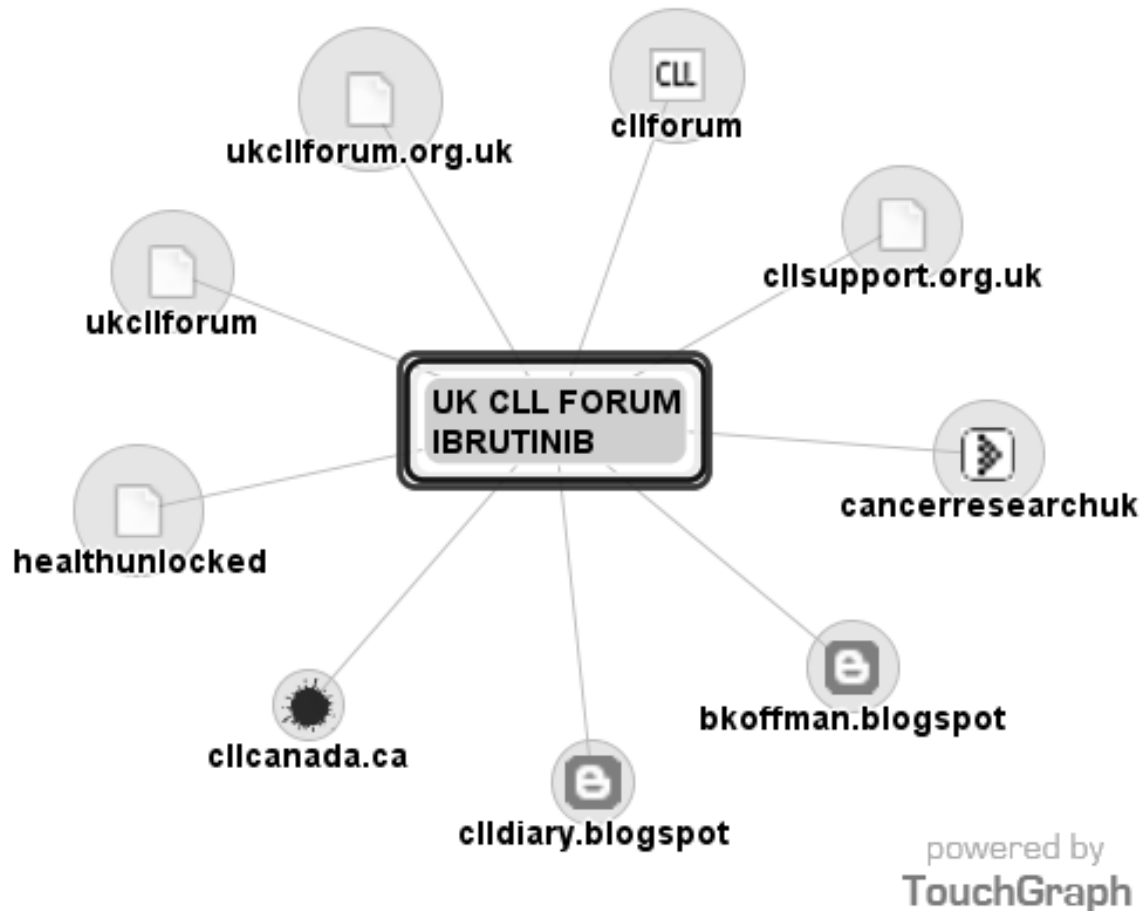


Figure 45: TOUCHGRAPH (2014) Network Connections for inks from UK CLL Forum discussion thread entitled 'ibrutinib', September, 2014 [Network Map]. [Online] Available at: [www.touchgraph.com](http://www.touchgraph.com) [Accessed 03/12/2014].

For a variety of reasons, some discussed earlier, not all clinicians go out of their way to seek out and suggest relevant trials to their patients. In May, 2014, the National Institute for Health Research (NIHR) marked International Clinical Trials Day with the launch of its UK 'OK to ask' campaign promoted across national mainstream and social media. Simon Denegri, NIHR



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National Director for Patient and Public Participation and Engagement in Research highlights the reciprocal benefits of trial involvement when he points out that:

Much of the life-saving clinical research carried out in the NHS could not happen without hundreds of thousands of patients and carers stepping forward every year to take part. Those who volunteer in this way report a range of benefits and are pleased to be potentially helping others like them with the same condition. NIHR's national 'OK to ask' campaign taking place on International Clinical Trials Day is about encouraging many more people to ask their doctor about being in research as part of their care and treatment and highlighting that they have a right to information about 'relevant and appropriate' research under the NHS Constitution. (cited in NIHR CRN,2014)

Although articulated primarily as something patients can do to advance the cause of medical research, Denegri finishes the statement by encouraging patients to see information about and access to trials appropriate to their condition as their 'right' under the terms of the NHS constitution.

The emphasis is on patients taking responsibility to pursue that right themselves, and not waiting to be offered it by their clinician. This campaign found its way into the CLL networks in the UK in a number of forms, and I will look briefly here at a posting to the UK CLL forum by Member 'Nick' (Hairbear elsewhere). The final post in a 12 post thread entitled simply 'ibrutinib', the contribution is pitched in relation to the planned closure of the ibrutinib compassionate access programme in September, 2014, and the need to share news of new UK clinical trials that might take over in the provision of access to CLL patient groups. Introducing the 'OK to ask' campaign, Nick cites Denegri in his post:

We want patients to know that research is happening in the NHS and to enable them to have access to information about local opportunities and to feel empowered to speak to their doctors

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about the possibilities, commented the NIHRs Simon Denegri. This campaign is about getting that conversation going, and letting patients know that they don't have to wait to be approached by their doctor or nurse. (Nick, UKCLL forum, 2014)

The shift on emphasis, or indeed responsibility for pursuing trials information away from health professionals and onto the patient in Denegri's quote is interesting, and again follows the ethos of patients actively pursuing information as their 'right'. Nick picks up on the patient-empowerment ethos of the campaign to preface a couple of links to campaign information:

If you are approaching treatment it's OK to Ask your doctor about a clinical trial.  
<http://www.nihr.ac.uk/newsroom/the-nihr-%27ok-to-ask%27-campaign-encourages-patients-to-take-part-in-research/1192>  
<http://www.ct-toolkit.ac.uk/news/its-ok-to-ask-the-nihrs-new-patient-empowerment-campaign>

Before listing relevant CLL trials currently running or planned in the UK, along with details, layman summaries, and links to more generic trials information through the UK Clinical Trials

Gateway:

You may interested to know that the latest CLL trial, FLAIR, opened last week in Leeds and we should start to see this opening at other hospitals around the UK in the next few weeks.

FLAIR: Front-Line therapy in CLL: Assessment of Ibrutinib + Rituximab to assess whether IR is superior to FCR in terms of progression-free survival

Participants will be 555 randomized [sic] on a 1:1 basis to receive either FCR or Ibrutinib+R.

Planned Sample Size: 754; UK Sample Size: 754

<http://www.ukctg.nihr.ac.uk/trialdetails/ISRCTN01844152?view=healthprofessional>

This is the latest of the new kinase inhibitor trials that are now open. Others include

IcICLE: (recently opened) Ibrutinib

<http://www.ukctg.nihr.ac.uk/trialdetails/ISRCTN12695354>

layman summary <http://www.cancerresearchuk.org/cancer-help/trials/a-study-looking-ibrutinib-chronic-lymphocytic-leukaemia-icicle>

For other UK CLL trials info: NCRI study group portfolio map PDF

[http://csg.ncri.org.uk/wp-content/uploads/2013/10/NCRI-CSG\\_HaemOnc-Portfolio-Map\\_Chronic-Leuk-.pdf](http://csg.ncri.org.uk/wp-content/uploads/2013/10/NCRI-CSG_HaemOnc-Portfolio-Map_Chronic-Leuk-.pdf)

UK Clinical Trials Gateway:

<http://www.ukctg.nihr.ac.uk/search?query=keyword:chronic+lymphocytic+leukaemia&resultsfrom=1&resultsto=20000&advanced=true&pagesize=20000>

If you are approaching treatment and interested in a trial, now would be a good time to chase this up with your doctor.

A posting such as this is information rich, and demonstrates how key actors in specific localized disease communities might respond to larger networked endeavors to empower patients such as the 'OK to Ask' Campaign. The importance of key actors like Nick (and Chaya Venkat) can't be overestimated in bringing patients closer to empowerment through localized network activity, vividly bringing to life Bruno Latour's contention that a network that is expanding is better termed a 'work net' with emphasis on the 'work' (Latour, 2007).

Although some patients in the community will undoubtedly have the resources to pursue this information independently, this study has shown that even those patients tapped into narrative networks surrounding their disease have varying levels of engagement, and different degrees of understanding of what they encounter therein. The momentum of activity in response to the campaign in CLL networks will be boosted or maintained by those members willing to put in the

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legwork to provide resources for relevant information for others, as demonstrated here in Nick's post. Of course it is important as ever to bear in mind that those not tapped into such networks may have little or no knowledge of their disease outside what their doctors tell them.

**Appendix 15: List of translations of this PhD research currently in circulation**

*a) Hanging with 'the Chronics' Online: Autopathography and Narrative Associations in an online support group for Chronic Lymphocytic Leukaemia – abstract of paper given at Interdisciplinary.net 'Chronicity' Conference, Oxford University, 2012 and published in conference proceedings.*

*b) (Not just) In the Blood: ppt. presentation of research (with notes) from CLLSA UK Pan-European Advocacy Meeting, Cambridge, 2014. List of attendees at presentation also included.*

*c) Screenshots and URLs from 'Julia's Story: From CLL diagnosis to a doctorate study of how CLL people use the internet' on Patient Power, YouTube, and CLLSA UK website.*

*d) Screenshots and URL for Panel discussion from the CLL Support Association UK Patient Meeting in Cambridge, 21st June, 2014: CLLSA UK and YouTube.*

*e) Copied e-mail exchange documenting use of PhD data to review and inform patient information booklet for the Leukaemia and Lymphoma Research Charity (to be known as 'Bloodwise' from September, 2015) 2014.*

*f) Forthcoming events at which PhD data will be presented.*

**Appendix 15 (a): Abstract for Hanging with the “The Chronicles” online: Autopathography and Narrative Associations in an online support group for Chronic Lymphocytic Leukaemia – Presented at ‘Chronicity’ Conference, Oxford University, 2012**

Often externally invisible, and currently considered incurable, chronic lymphocytic leukaemia

(CLL) occupies several stages from indolent, through progressive, to terminal in some cases.

Variable patterns of disease progression position those with the condition in ongoing

negotiation with various points on a conceptual continuum between “wellness” and “illness”

with no definitive hope of cure. This ethnography of a chronic disease traces networks of

narratives surrounding CLL coalescing in and around the hub of an online support

community for people with the disease. Amongst other examples, these include patient

stories, medical research papers, online advice for those diagnosed with CLL, medical results

and documents. Diagnosed with CLL myself, I have embodied investment and full member

status in the research field. Using autopathographic narrative (Couser, 1997), the work will

draw on Latour’s object-oriented philosophy to map ways in which these narrative objects are

transported and translated around varying experiences of the disease. Autopathography and

online ethnography allow for expression of the lifeworlds of those experiencing CLL, and a

revealing of how lived experiences of CLL intersect with the texts and technologies that

define CLL as a disease through, CLL research, diagnostics, treatment protocols, online

support groups and professional support. Particular attention will be given to the impact of

differing relations with time experienced by those with chronic disease on their lifeworlds.

This paper outlines the project design for my doctoral project on narratives in an online

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community for those with CLL, and summarizes work in progress. Through this process of early-stage sharing of work to date, the paper considers strategies for innovative and effective presentation of complex assemblages of data incorporating biographical and autobiographical narrative alongside a range of broader narrative, cultural, and technological objects in exploring the experiences of knowing, understanding, and living with chronic, incurable disease. Keywords: Chronic Lymphocytic Leukaemia; auto-ethnography; online support community; actor network theory; narrative; autopathography. Full paper available at:

[http://repository.falmouth.ac.uk/300/1/RR\\_Hanging%20with%20the%20Chronics\\_021013\\_nid252.pdf](http://repository.falmouth.ac.uk/300/1/RR_Hanging%20with%20the%20Chronics_021013_nid252.pdf)

**Appendix 15 (b): Ppt. Presentation of research given at CLLSA UK Pan-European Advocacy Meeting, Cambridge, 2014, with list of attendees and affiliations**

<b>First name</b>	<b>Surname</b>	<b>Organisation</b>	<b>Position/role</b>	<b>Web site address</b>	<b>Country</b>
xxxxxx	xxxxxx	CLL Support Association	CLLSA Chair, CLL patient	<a href="http://www.clisupport.org.uk">www.clisupport.org.uk</a>	UK
xxxxxx	xxxxxx	CLL Support Association	CLLSA advocacy CLL patient	<a href="http://www.clisupport.org.uk">www.clisupport.org.uk</a>	UK
xxxxxxx	xxxxxxx	CLL Support Association	CLLSA advocacy CLL patient	<a href="http://www.clisupport.org.uk">www.clisupport.org.uk</a>	UK
Nick	York	CLL Support Association	CLLSA trustee, CLL patient	<a href="http://www.clisupport.org.uk">www.clisupport.org.uk</a>	UK - Wales
Ceri	York		CLL carer/facilitator		UK - Wales
Julia	Kennedy	Falmouth University PHD research CLL on-line	CLL advocate, CLL patient	<a href="http://www.falmouth.ac.uk/content/julia-kennedy">www.falmouth.ac.uk/content/julia-kennedy</a>	UK
George	Follows	UK CLL Forum & Cambridge University Hospitals	CLL Clinical lead, CLL forum Chair	<a href="http://www.ukcllforum.org">www.ukcllforum.org</a>	UK



xxxxxx	xxxxxxx	Leukaemia Care	CEO, CLL patient?	<a href="http://www.leukaemiacare.org.uk">www.leukaemiacare.org.uk</a>	UK
xxxxxxx	xxxxxx	Lymphoma Association	CEO	<a href="http://www.lymphomas.org.uk">www.lymphomas.org.uk</a>	UK
xxxx	xxxxxxx	Leukaemia & Lymphoma Research	Head of Patient Services	<a href="http://www.leukaemialymphomaresearch.org">www.leukaemialymphomaresearch.org</a> <a href="http://www.leukaemialymphomaresearch.org">.uk</a>	UK
xxxx	xxxxxx	Older People's Advocacy Alliance	CEO	<a href="http://www.opaal.org.uk">www.opaal.org.uk</a>	UK
xxxxxxx	xxxxxx	Patient Power/Brandcast media		<a href="http://www.brandcastmedia.com">www.brandcastmedia.com</a>	UK
Andrew	Schorr	Patient Power EU	Founder, CLL patient	<a href="http://www.patientpower.eu">www.patientpower.eu</a>	Spain
xxxxx	xxxxx	CML Advocates network	Co founder	<a href="http://www.cmladvocates.net">www.cmladvocates.net</a>	Israel
xxx	xxxxxxx		CLL patient advocate	<a href="http://www.miabonhomme1.wix.com">www.miabonhomme1.wix.com</a>	Belgium
xxx	xxxxx		CLL patient advocate		Ireland
xxxxxxx	xxxxx		CLL carer advocate		Ireland
xxxxx	xxxxxxx	SILLC	Board member	<a href="http://www.sillc-asso.org">www.sillc-asso.org</a>	France
xxxxxxx	xxxxxxx		CLL patient advocate		Ireland
xxxxxxx	xxxx		CLL patient blogger		Spain/Portugal

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xxxxxx	xxxxx		?? CLL patient advocate		Germany
xxxx	xxxxxxx		?? CLL patient advocate		Germany
xxxx	xxxxxxxx		CLL patient advocate		France
xxx	Xx xxxx	Hematon Leukemie en MDS	Board member	<a href="http://www.leukemie.nfk.nl">www.leukemie.nfk.nl</a>	Netherland
xxxxxx		Beat Leukemia		<a href="http://www.beat-leukemia.com">www.beat-leukemia.com</a>	? Italy

Figure 46: CLLSA UK (2014) List of attendees (and affiliations) at CLLSA UK Pan-European Advocacy Meeting, Cambridge, 2014 [Table].

## **(Not just) In the Blood: Presentation with Notes**

What I will do today:

1. Tell you how my doctoral research project In the Blood began
2. Give you a very brief overview of its aims
3. Draw out some of my main observations and findings into an advocacy context to underpin some of the work we'll be doing later

To cut a very long story very short indeed, back in February 2011, I visited my GP to get the results of a recent blood test. He told me I had CLL, that it was incurable, that he didn't know what my prognosis was, and that I should go away and LOOK IT UP ON THE INTERNET

I followed Drs orders and did just that – in that early process of researching to survive I was overwhelmed by the amount and range of information I found.

The researcher in me saw a gap in the market ...

Here was Tom Ferguson's informed, connected and empowered 'e-patient' at work – tapping into and sharing a wealth of information about this most common yet seemingly little understood of adult leukaemias, from the complex hard science of a disease poised at the crossroads of biomedical understanding, through its various global political-economies, to the existential impacts of living with a disease that produces lower emotional well-being scores amongst those that live with it than any other type of cancer ... (Shanafelt et al, 2007)



And if we look at the sites we'll see that they all function differently individually but connect as a network – facilitating information exchange across network boundaries - although some types more popular than others...

Core CLL sites link out into related sites: medical education, pharma press releases, benefits advice, trials sites, generic health related and everyday news...

A delicate and important eco-system of everyday advocacy *already* exists amongst members of the network ...

People are advocating in all kinds of ways for *themselves* (Seeking advice from other members online – going direct to databases for research - influencing treatment decisions through bringing online information into the clinical relationship with their Drs)

And indirectly for others by sharing their stories and their research findings

Or more directly, by actively seeking out research and sharing it across networks, setting up or becoming actively involved in managing sites and blogs

All important roles – but it is the latter – the organizers and innovators who are the KEY MEDIATORS in the network providing the frameworks within which the exchange of information and support takes place

Raising important issues for discussion amongst CLL patients across the network (Wayne Wells and recent discussion re CT scanning across networks)

Careful consideration needs to be given to how and when we harness that and take it to the next level – strategic, Political, awareness-raising, lobbying, and so on... whilst retaining the diversity and independence of the patient led communities

Much evidence of locally specific issues drawing on global networks of knowledge and support

- local both in terms of an individual's experience of their disease as located in their own body and social contexts

- And in terms of regional, national and international differences in care delivery systems, governance, and cultural attitudes (the disease shape shifts across these boundaries - but the concerns and trials of living with CLL have universal points of identification...
- Important point for advocacy across cultural and geographical boundaries
- (indymedia model)

Let's zoom into an analysis of core network use in 2012

**Small 'a' advocacy at work in the network**

39% shared research information

61% shared their own experiences

93% 'more informed' from online use

83% felt that helped living with CLL

79% discussed online info with Drs.

Around a third of all respondents did not actively post

?how to get these voices heard

***"Both CLL Topics and the ACOR List have been priceless tools for me. The diverse experiences of other CLL patients have given me the knowledge I need to live with this ailment and know I am not alone....the stories of other patients will enable me to deal with the next stages with less fear."  
(survey respondent 37)***



**Living with CLL: The over-arching themes**

Each dominant theme containing a number of specific issues  
Creating a detailed picture of what it means to live with CLL now

And this gives us the lead on areas that may need addressing

Where advocacy is working, or needs to work harder, at both everyday and more organized strategic levels

- **Diagnosis**
- Understanding CLL as a form of 'cancer'
- Struggling with watch and wait
- Lack of info at GP level
- Geographical Inconsistencies in allocation of specialist care

- **Prognosis**
- Making sense of stats
- Understanding significance of prognostic/predictive markers - Power or Paralysis?
- Inconsistencies in tests available
- **Treatment**
- Keeping up with new developments
- Access to trials/drugs
- 2<sup>nd</sup> best? Still doing chemo in the brave new world
- **Survival**
- Living in 'prognosis': Risky bodies/uncertainty/identity
- Psychosocial/cultural/economic issues
- Spiritual/existential :understanding limits of control/addressing mortality





**2. Just as we need to understand how each part of any machine we rely on relates to the others in order to function, we need to get the 'black box' off CLL online to see how *all* of the components work together to make it into the disease we recognize**

**But if we're honest, most of us aren't that interested how our machines are put together until we need to fix or modify them ...to make them work better for us...**

...and advocacy is essentially a process of doing just that – of recognizing where the circuitry breaks down for some of us and working together to try and make it function better ...

We may want to fix the fact that many of the challenging aspects of living with a chronic cancer of the immune system remain unrecognized

Or that new drugs get caught up in regulatory bureaucracy and don't make it to market quickly enough to save lives

Or are too costly to be broadly accessible

Or that our haematologists aren't talking to our dermatologists and too many of us are dying of melanomas, and so on

If we want to tinker with it, we must first understand the complex circuitry holding CLL together as a single entity

To advocate successfully, we must be aware of all of the actors in the networks, human and non-human

Connect genetic mutations at cellular level to that tube of blood where it all began for most of us – to the laboratory technology, research and funding that progresses diagnostic,

prognostic and treatment options, to the medical education that trains and frames our clinicians, to the pharmaceutical industry and those who invest in and regulate it, to the governance of global and local health care systems, to the employment and benefit laws that impact on people with CLL, through the information technology that allows us to share our experiences, to the cultural attitudes that frame the stories we all tell each other and ourselves about this disease...

If we want to fix or change any part of the many faces of CLL – we really need to see the bigger picture...

### **3. The expanding ‘common-wealth’ of networked information allows us to do just that**

It smashes apart traditional hierarchies of political and knowledge sharing hierarchies

It replaces them with collaboration, participatory politics and grassroots activism online...patient ‘centred’ care evolves into the model of the ‘networked patient’ (and Dr)

It generates new forms of capital – for instance, those good at inspiring ‘identification empathy’ in online communities become stand-out actors and advocates.

One caveat – we need to consider ways of being more inclusive for those voices currently going unheard...Lurkers are by no means IN-active, but their voices and actions are currently unharnessed...

**To finish - we are undoubtedly in the best environment to date in which to advocate for this one-time ‘Cinderella’ of the disease world**

A number of external factors are influencing the fact that CLL is finally getting to go to the ball, BUT online access means we can *all* play a role in becoming our own collective fairy godmother...

Thankyou

Julia Kennedy, Falmouth University, June 2014      [julia.kennedy@falmouth.ac.uk](mailto:julia.kennedy@falmouth.ac.uk)

If citing any material from this presentation, please contact me for citation details.

Image removed due to copyright restrictions

**Figure 47: CLLSA UK (2014) Homepage of CLLSA UK showing image from the CLLSA UK Pan-European Advocacy Meeting, Cambridge, 2014 [Screenshot]. [Online] Available at: <http://www.cllsupport.org.uk/home> [Accessed 02/08/2015].**

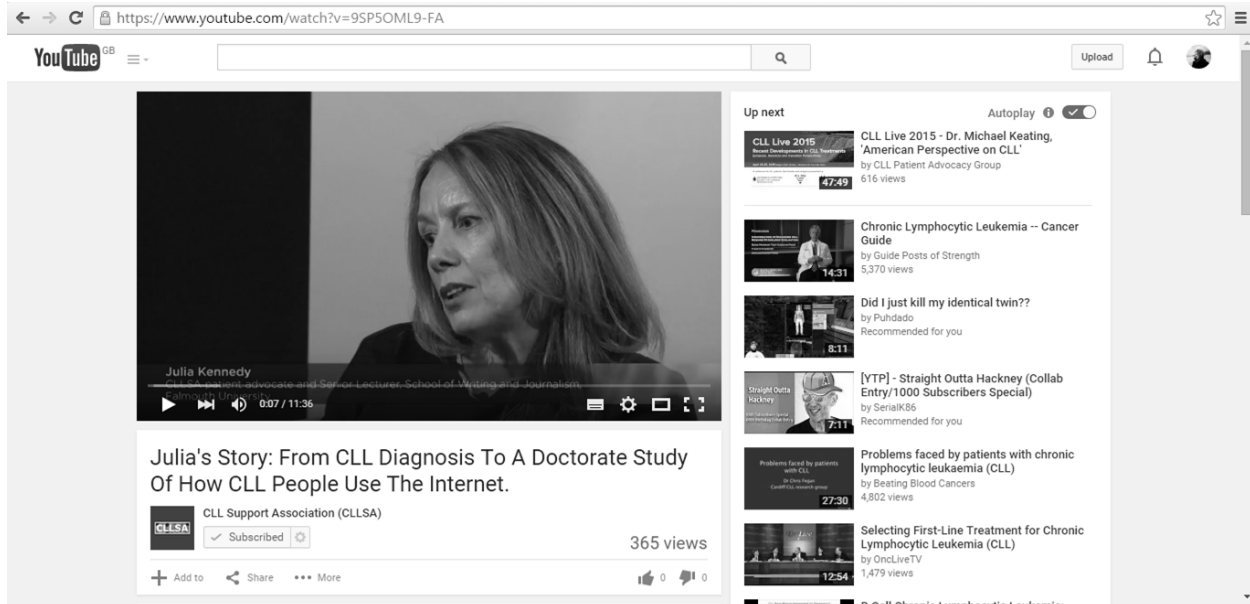
## Appendix 15 (c): Screenshots and URLs from videos discussing this work online



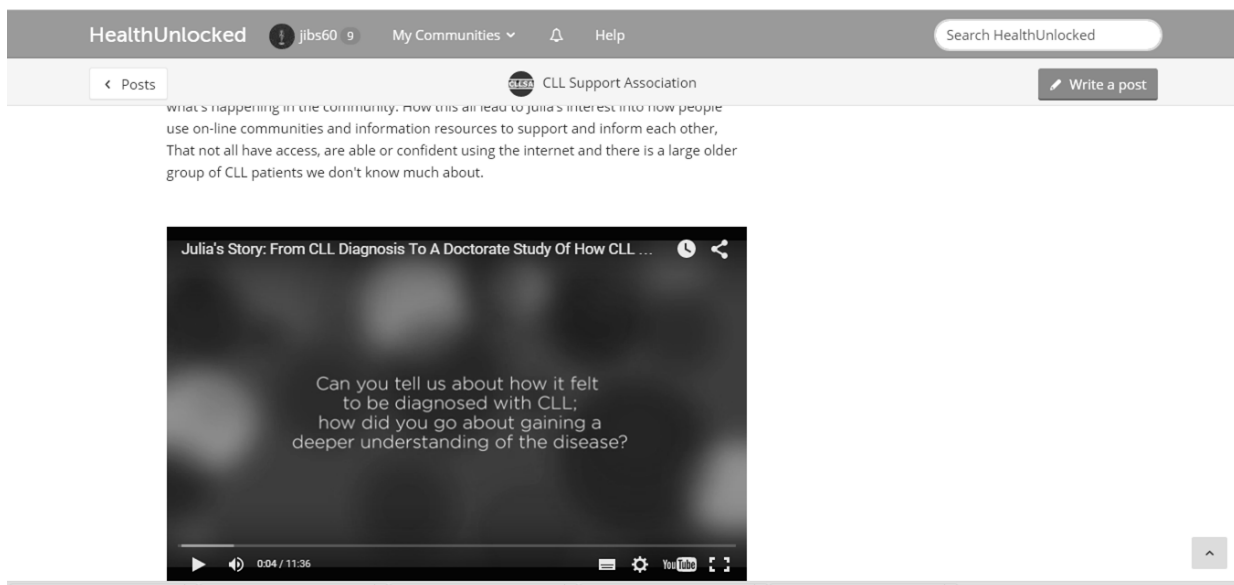
**Figure 48: PATIENT POWER EU. (2014) 'Julia's Story: from CLL diagnosis to a doctorate study of how people use the internet' [Video Screenshot]. [Online] Available at: <http://www.patientpower.eu/videos/julias-story-from-ctl-diagnosis-to-a-doctorate-study-of-how-ctl-people-use-the-internet/> [Accessed 28/07/2015].**

### **Julia's story: From CLL diagnosis to a doctorate study of how CLL people use the internet**

Julia shares with us: her experience of diagnosis with chronic lymphocytic leukaemia (CLL); her first questions and the general doctor's knowledge; how being selective when sourcing information is important; the importance of relationships and working together with her doctors, and following what's happening in the community; how this all lead to her interest into how people use online communities and information resources to support and inform each other; and that not all have access to, are able or confident using the internet and there is a large older group of CLL patients we don't know much about. (Patient Power Eu., 2014)



**Figure 49: YOUTUBE (2014) 'Julia's Story: from CLL diagnosis to a doctorate study of how people use the internet' [Video Screenshot]. [Online] Available at: <https://www.youtube.com/watch?v=9SP5OML9-FA>. [Accessed 28/07/2015].**



**Figure 50: CLLSA UK HEALTH UNLOCKED (2014) 'Julia's Story: from CLL diagnosis to a doctorate study of how people use the internet' [Video Screenshot]. [Online] Available at: <https://healthunlocked.com/cllsupport/posts/131147447/archive-of-latest-cllsa-videos> [Accessed 28/07/2015].**

**Appendix 15 (d): Panel discussion from the CLL Support Association UK Patient Meeting in Cambridge, 21st June, 2014: CLLSA UK and YouTube**

Image removed due to copyright restrictions

**Figure 51: Panel discussion video published on 26 Jun 2014 [Screenshot]. [Online] Available at: <https://www.youtube.com/watch?v=9882LmKVMRc> [Accessed 28/07/2015].**

In this video from the CLLSA UK Patient Meeting in Cambridge, 21st June, 2014, Patient Advocate Andrew Schorr chairs a panel of UK patient advocates in a discussion of the important roles that advocacy can play in living with and raising awareness of less understood diseases such as CLL. From small 'a' to large 'A', the panel traces the impact of advocacy from the personal to the political and the local to the global.

Kath Parson from OPAAL (Older People's Advocacy Alliance), adds her professional perspective to the experiences of CLL patient advocates Julia Kennedy and Tricia Gardom. Andrew, Julia and

Tricia share their experiences in the transformation from patient to advocate and discuss what motivated them.

The panel concludes that advocacy works at a number of levels, beginning with the immense day to day benefits that sharing experiences with other patients in support groups brings to those living with CLL. From the positive impacts on the sense of isolation, fear and powerlessness that often accompanies diagnosis, grow more strategic advocacy campaigns such as lobbying for improved access to costly transformational therapies among the CLL community. Finally, the panel considers the potential benefits to the patient and clinical communities of collective individual experience on-line providing a global insight into living with CLL. All agreed that, whilst face to face support was important, staying connected online was an increasingly effective source of networked empowerment. The panel strongly encouraged as many people living with CLL as possible to improve outcomes and raise awareness of the disease by getting involved in advocating for themselves and others (YouTube, 2014).



**Appendix 15 (e) E-mail exchange documenting use of PhD data to review patient information booklet for the Leukaemia and Lymphoma Research Charity, 2014**

*Inbox*

16 September 2014 10:03

Hi Julia,

Thanks very much for your email. Your PHD data sounds really interesting – would I be able to access this once you’ve completed the work? I’m sure there’s lots in there that would be valuable to us.

Thanks again for your help, and if we can use your skills and experience again in the future that would be terrific.

Kind regards,

Jon

Kennedy, Julia

*Sent Items*

09 September 2014 11:02

Jon,

You're very welcome.

I would add that I have a wealth of qualitative data from CLL patients about their experiences of living with CLL, particularly in relation to internet use, gathered during my PhD. I'm writing up at the moment and intend to publish it as a whole, and as a number of individual research papers on discrete topics once it is complete (hopefully in the New Year 2015).

If I can be of any further help to you as a patient/researcher, just let me know.

With kind regards.

Julia

Julia Kennedy

Senior Lecturer

School of Writing and Journalism

Falmouth University

E-mail: [julia.kennedy@falmouth.ac.uk](mailto:julia.kennedy@falmouth.ac.uk)

Tel: 01326 370400 ext 1715

Jon Hoggard [JHoggard@beatingbloodcancers.org.uk]

*Inbox*

08 September 2014 11:43

Dear Julia

My name is Jon Hoggard and I'm the patient information manager at Leukaemia & Lymphoma Research.

I just wanted to write to thank you for taking the time to review the new CLL booklet, especially at such short notice! I'd also like to apologise for the delay in getting back to you.

We really appreciated your comments and have done our best to include them as much as possible, with guidance from our Medical Advisor. The information is always evolving however, and so we welcome any further comments you might have.

I'm arranging to send some printed copies to Sarah at the CLLSA, but if you would like me to send you a copy of the booklet directly, please reply with your contact address and I'll gladly post one out to you.

Thank you once again for your help with the project.

Best wishes,

Jon Hoggard

Patient Information Manager

Leukaemia & Lymphoma Research

*Kennedy, Julia*

Actions

**To:**

JHoggard@beatingbloodcancers.org.uk

**Cc:**

nick.york@cllsupport.org.uk

*Sent Items*

11 August 2014 14:00

Hi Jon,

I am among those CLLSA members asked by Nick to take a quick look at the new booklet and comment.

Generally, I think it to be a good resource for the newly diagnosed. The tone is accessible without being patronising (a major problem in a lot of literature for the newly diagnosed in my view).

Just a couple of observations then, based on a very quick look given the time-frame:

1) I think more emphasis could be placed on the importance of keeping informed and supported through self advocacy online (or encouraging people to get someone to help them with this if they are not particularly computer literate). 83% of the 260 CLL patients I surveyed for my current doctoral project about online use and information/support seeking behaviour among CLL patients said unequivocally that using online resources has helped them to live with CLL. A similar significant majority said that discussing their research with their medical teams had led to them feeling more able to understand their clinicians'

decisions in respect of their care and, in some cases, had even led to selecting a different approach in response to new treatments, trials and protocols learned about online after discussion with their doctor. The emotional support gained from getting into dialogue with other CLL patients is also of significant importance for CLL patients (who currently record emotional well being related quality of life indexes below those of patients with any other form of cancer). Not all CLL patients will see a CLL specialist, as you point out in the booklet, so I think it is important to really emphasise the benefits of gaining support, and keeping up to date with current treatments and trials through the use of reliable sites such as CLLSA.

2) When I received my own recent FCR treatment, I felt I didn't get enough information about following a neutropenic diet during my extreme neutropenic phases. I notice that this isn't mentioned anywhere in the treatment information, so maybe a couple of words about food hygiene and a neutropenic diet would be useful so patients can raise it with their medical teams for further info if needed.

3) I was under the impression that inconsistencies in laboratory testing made Zap-70 a controversial marker in practice, and that many centres don't offer it?

4) Finally - perhaps more emphasis on getting information on trials given the current rapidly evolving treatment landscape. Despite mentioning new treatments in the pipeline, the booklet gives the impression that FCR is really still the only way forward unless you are 17p deleted or refractory in some other way. I understand the difficulties of raising hopes for new treatments which may not be available to all, and are still in trial in the UK, but perhaps a link to the UK clinical trials gateway <http://www.ukctg.nihr.ac.uk/default.aspx> somewhere so patients can at least see what's out there and raise this possibility with their doctors. Many patients are prepared to travel to different centres to get on a trial, but if their own hospital doesn't offer it and isn't a specialist CLL centre, they may never get to

hear about trials elsewhere in the country that they may be eligible for (another reason to encourage them to get online...)

As I say though, generally an informative and comprehensive guide in an accessible and well-designed format that I think will be of real use to the newly diagnosed.

All the best.

Julia

Julia Kennedy

Senior Lecturer

School of Writing and Journalism

Falmouth University

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Tel: 01326 370400 ext 1715

**Appendix 15 (f): Forthcoming Presentations of PhD Data**

Keynote Invitation accepted for:

# ***ePatients***

***The Medical, Ethical and Legal Repercussions of Blogging and  
Micro-Blogging Experiences of Illness and Disease***



**Queen's University Belfast, 11-12 September 2015**

<https://epatientsconference.wordpress.com/2015/06/24/programme-and-registration/>

<http://blogs.bmj.com/medical-humanities/2015/03/22/epatients-the-medical-ethical-and-legal-repercussions-of-blogging-and-micro-blogging-experiences-of-illness-and-disease-call-for-papers-and-conference-details/>

*Guest speaker invitation accepted for:*

September 2015



## **Bristol - Wales & West - Members Meeting**

Registered Charity No 1113588, [www.cllsupport.org.uk](http://www.cllsupport.org.uk)

Dear Member

We would like to invite you to a Members' meeting of the CLLSA at

**Armada House, Telephone Avenue, Bristol, BS1 4BQ**

**September 28<sup>th</sup> 2015, 10:30 – 16:00 hours**

Travel & parking details are available [here](#)

Lunch and refreshments will be provided free of charge.

There is no charge to attend, the purpose of patient meetings is for you, the patient, carer or friend to meet other people living with CLL, and to exchange experiences and learn from expert speakers.

The provisional programme for the day (see below) provides presentations from:



- Professors Chris Fegan and Chris Pepper from Cardiff School of Medicine discussing the CLL treatment and care landscape, new treatments, clinical trials, prognostics and latest developments in prognostic testing
- Julia Kennedy CLL patient, senior lecturer in journalism Falmouth University discussing CLL and her PHD study of how people come together to make sense of living with a chronic disease in a contemporary landscape
- Penny Brohn Cancer Care, discussing self-help techniques for living with CLL
- CLL patient & CLLSA volunteer (anonymous) The Patients View

<http://www.clisupport.org.uk/civicrm/event/info?reset=1&id=28>