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Beyond Science Communication: a service design approach to building mutual stakeholder understanding in the development of novel biotechnologies

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Traditionally, designers communicated from one knowledge area to another largely through graphics, using conventional linear models where information is provided in a unidirectional flow from the experts (who know) to non-experts (who don't know). This is problematic because the communication is based on experts' assumptions about the 'audience' and does not necessarily understand or address audiences' actual concerns and existing knowledge or enable audiences to interact with the knowledge. Additionally, when we consider the distinct forms of knowledge, such as scientific - explicit codified elements, and tacit - informal processes and experience based on know-how - we need to find ways to reconcile knowledge-sharing between them. To counter this top-down and passive approach to communication, designers have a role in shaping knowledge sharing between the scientific and tacit by involving diverse stakeholders in action-orientated activities that are characterized by social interaction. Drawing on early findings and insights from design researchers working in the public engagement work package of Pharma Factory, an EU H2020 pharmaceutical biotechnology innovation project, this paper argues for a service design approach to healthcare communication, taking into account multiple stakeholder perspectives in knowledge co-creation and interpretation. The value of a more democratic, open and bidirectional approach to healthcare communication and 'public engagement' is considered, along with challenges and limitations.

Keywords: service design, co-design, biotechnology, mutual understanding, multidisciplinary

Introduction

Multidisciplinary working has, in recent years, become a desirable feature of science & technology projects funded by the European Commission's Horizon 2020 programme. In particular the inclusion of 'social sciences and humanities' has been cited as being particularly important (FET Advisory Group 2016). This has provided design researchers with the opportunity to work in H2020 projects, such as the Pharma Factory project, where previously their value would not have been considered. While the FET Advisory Group warns against paying 'lip service' to the inclusion of other disciplines, the challenge of describing the value of design research for such projects remains significant. Within biological sciences the traditional role of design might be to support science communication through graphics and exhibition design (Burns et al 2003); with a move towards increasing democratic ways of involving the public in open dialogue around technological developments (Irwin, 2006), design can interactively and collaboratively engage in co-producing knowledge for new technological futures.

Design's role as a process-orientated and facilitatory set of practices is still relatively new and unfamiliar with disciplines such as the biosciences; design, with its naturally human-centred mindset and creative practices, is still often conceived as focused on translating the complexities of codified knowledge into digestible and entertaining forms. In these situations, designers might adopt 'tricky tactics', being invited into the fold on the premise of established ideas of designs' contribution, before prompting, provoking, adapting and reframing that contribution in response to presented situations, adding value beyond what was anticipated (Fisher & Gamman 2018).

Pharma Factory focuses on four novel pharmaceutical technologies being developed using Plant Molecular Farming (PMF), a) an enzyme for treating Lysosomal Storage Disorders (LSDs), b) an edible vaccine for farmed fish, c) a molecule for treating HIV and, d) a diagnostic kit for Sjögren's Syndrome or Rheumatoid Arthritis. Each technologies development sits within a specific work package and is located at different stages of research and development. Two strategic work packages straddle the technologies, focusing on public engagement and regulatory pathways. A team of design researchers from University of the Arts London, collaborating with social scientists from St George's University of London were tasked with the public engagement package. Applying service design principles and co-design methods the team aim to understand opportunities and challenge barriers and for public acceptance of these new pharmaceutical technologies.

Service design is established in healthcare settings in Europe (Springham & Robert 2015, Bailey et al. 2019) and in the global south (Tsekleves et al. 2019), to address public health issues, involving multiple stakeholders in co-design processes to innovate and deliver new and improved services for a range of health and social care contexts. Less common is the application of service design at the very front end of biomedical research such as the Pharma Factory project. The adaptability of co-design tools and methods makes them ideally suited to this challenge, as they seek to avoid assumptions and first understand a person's experience, then to enable that person to co-design an alternative future (Sanders & Stappers 2008).

Whereas service design is most often used to design services (with or without a product focus), this research focuses on adapting these methods to facilitate the co-creation of knowledge, enabling mutual understanding of the value of novel technologies between stakeholders and scientists. In this frame the 'service' element is a co-created shared understanding of the value of that technology at

different points of the stakeholder's current and future experience (Akoglu & Dankl 2019; Sanders & Stappers 2008).

The purpose of this research approach for Pharma Factory is twofold:

1. to understand the value of the technologies afforded by PMF to a range of stakeholders.

2. to understand the perception of genetically modified (GM) plants when used within the context of pharmaceuticals, providing potential narratives and language that could be used to challenge (assumed) barriers to acceptance.

Beyond science communication

Science communication - or 'the deficit approach' (Bubela et al. 2009) - can be understood as the unidirectional flow of information from scientific knowledge domains to lay audiences to fill apparent gaps in understanding. Often this includes assumptions about what those audiences want or need to know, and what they already know. Science communication has evolved to some extent to include 'audience research' but in doing so there is the additional risk of promising too much in order to engage and entertain those audiences (Bubela et al. 2009). Once an understanding of an audience's values or expectations of emerging biotechnologies has been achieved, there is an ethical responsibility to ensure that the communication 'frame' doesn't obscure the specificities of the science, which can damage trust. These shortfalls have been recognized within the field of biotechnology with authors calling for greater focus on 'dialogue' with lay people (Bubela et al. 2009; Burns et al 2003). While multidisciplinarity is seen as essential in contemporary critiques of science communication (Fischhoff 2013), the value of design has not been considered in this context.

A service design approach using co-design tools and methods can help to address these challenges of 'science communication', as it goes beyond 'audience research' to involve the participants in validating co-created artifacts, and in subsequent design of artefacts and events informed by the resulting co-created knowledge (Chamberlain & Partridge 2017). As a methodology distinctly different from the biosciences and social sciences, design research arguably provides something fundamental that science communication has been missing. Being flexible, problem-oriented and empathic, co-design provides designers with the tools to build a bridge between the highly specific, but abstract science with its codified language, and the values of specific stakeholders or wider audiences. By revealing hidden values and providing narratives or 'frames' (Burns et al 2003) it makes the science empathic and relatable to wider audiences. Furthermore, co-design provides the means to build that knowledge through an iterative, guided process. In this way the methods and tools challenge assumptions and reveal deep-seated value systems through participatory research activities.

In Pharma Factory, the research process involves co-designing first with the scientists, then with stakeholder groups, feeding back to the scientists and then communicating with wider audiences (fig. 1). Akoglu & Dankl (2019) argue that mutual learning and understanding are a central outcome of a co-creation design research approach, building empathy amongst stakeholders. This makes co-design well-suited to the challenges of communication in healthcare where new technologies are

highly specific, and their production and use impact particular groups of people with non-standard needs and values.

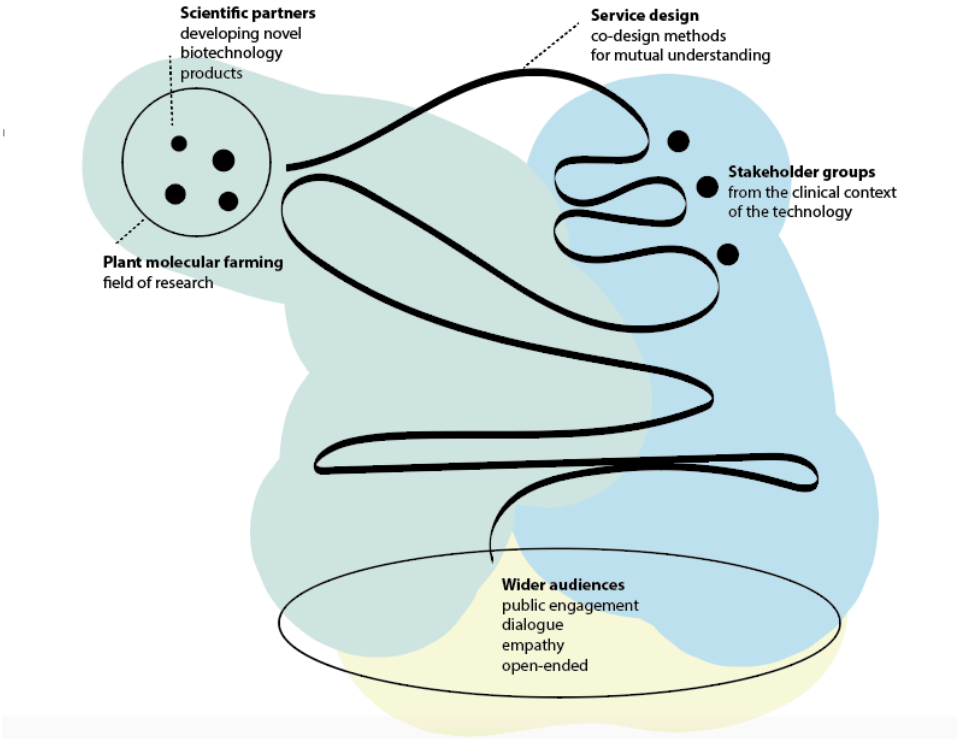

Figure 1: Service design research process pathway in Pharma Factory

Methodology

This project uses a service design approach with co-design tools and methods - some adapted from standard tools, and others contextually designed (Chamberlain & Partridge 2017). The approach of the design facilitation was in the spirit of emergent practice as described by Aguirre et al (2017) which relates to a 'research by design' methodology: "designers fly in complex patterns—they act as both participants and facilitators. In the latter role, they must foster participant interactions that generate emergent material. Such emergence is "brought into existence by the way a whole [event] is bound together by substance and order through relationships and connections." (Aguirre et al 2017:199). In the current project mutual understanding can be considered the 'emergent material', afforded through revealing hidden values and challenging assumptions, in turn leading to translation and bridge-building between biotechnology, stakeholders and wider audiences, as described earlier.

The design research team first designed and delivered co-design workshops with the scientific partners to identify and understand the stakeholders connected to the novel technologies and to explore scientists' assumptions about the value of their technology to them. After analysis and sensemaking phases, the design researchers sought to engage a range of stakeholders, designing and developing workshops for each group recruited. Currently, the design researchers are recruiting, designing and conducting this 'stakeholder engagement' phase of the research. Early findings presented relate to the first of these stakeholder workshops conducted in February 2020. As described earlier, once complete the findings of the engagement will be reported back to the

scientific partners and the European Commission to inform their ongoing work, as well as providing valuable insights to inform public engagement activities, including interactive exhibitions and pop-up events within the timeframe of the Pharma Factory project.

As the research is ongoing and there are limitations in reporting the full findings at this stage, this paper reflects on one of the four technologies - the production of a molecule to be used in the treatment of Lysosomal Storage Disorders (LSDs) - and the discussions that took place in a workshop with 8 specialist Pharmacists. The aim here is to discuss how a service design approach may have contributed to original insights and understanding of stakeholders' perceptions and values, and how this supports the production of mutual understanding.

A short case summary

This case summary reflects briefly on the first Stakeholder Workshop conducted within the Pharma Factory project with Pharmacists as described above.

A 'Project Glossary' was co-designed, to enable the translation of some of the codified scientific language and key concepts into narrative tools, so that workshop participants could easily engage with the technology (fig. 2).

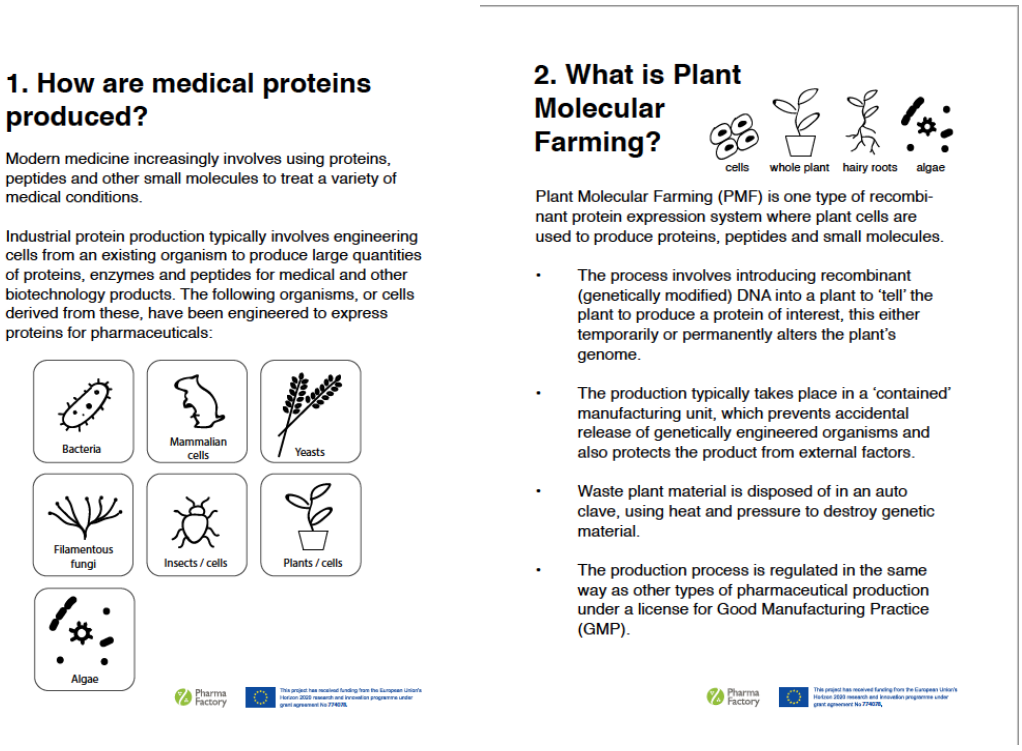

Figure 2: Biotech concepts and terms were translated into narrative workshop tools

During the first activity in the stakeholder workshop - an ecosystem map - pharmacists revealed an interesting micro-network of stakeholders involved in treatment provision for LSD patients. During the task pharmacists were encouraged to think about who they interact with during their work with these particular patients. Design facilitators were then able to prompt additional questions iteratively, building detail incrementally, supported by worksheets for visual reference. Through this exercise the important roles of 'Prescribing Nurses', 'Specialist Nurses', 'Homecare Coordinator' and

'Dietician' were identified, which added detail to the 'hospital' as a general stakeholder. This challenges assumptions that pharmacists are the sole operators bridging between prescription (clinician) and treatment (patient) and are in fact part of a more complex network of actors (fig. 3).

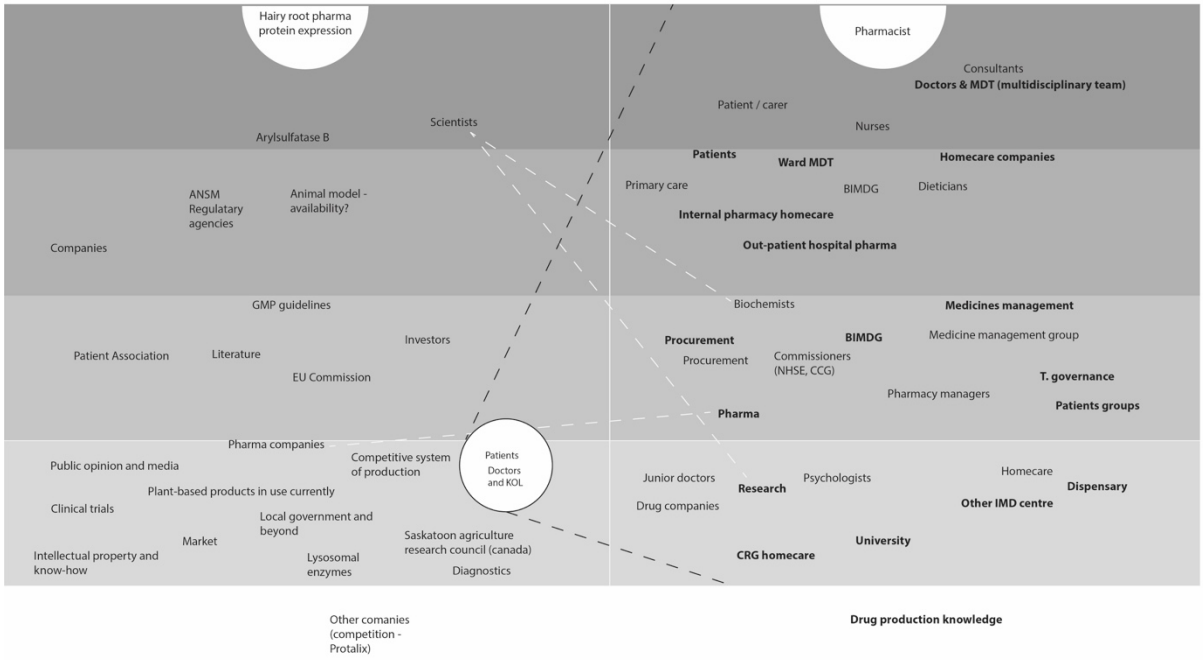

Figure 3: A visual comparison of the scientific partners' ecosystem map with the pharmacists' map, showing the expansion of 'hospital' into a more detailed network of actors.

In a subsequent activity the scientists were fairly accurate in their assessment of the value of their technology to patients and clinicians. They identified 'safety' and 'efficacy' as key values and this was echoed by pharmacists. However, the definition of 'efficacy' was seen as incredibly important to the pharmacists and how this translated into clinical impact. There were additional values that the scientists had overlooked such as 'ease of use' when administering the drug, and 'the novelty value' as patients seek to try new treatments to improve their condition.

The workshop also provided insights around terminology when engaging general audiences. For example, the term 'recombinant' was familiar to the participants and normalized in relation to pharmaceutical production, whereas 'GM' appeared to be rarely used or associated with pharmaceuticals. When participants were given information about PMF and the term 'GM' was introduced for the first time, they immediately switched to a more populist view of the implications, seeing that 'the media' could have both a positive and a negative role in how people perceive the new technology (fig 4). Interestingly, when focusing on the actual medication, whether it was produced by one method or another (for example, recombinant plant or mammalian cell, or chemical) was not a concern to the pharmacists, but as soon as they were encouraged to zoom out and think from the general perspective, they began to think about how the use of GM plants could cause concern to 'the public'. This raises the question of whether those who are not directly benefiting from the products would be more likely be concerned by the use of GM.

Speculative prototyping provided participants with the tools to address this challenge: what would they do to allay peoples' fears of the technology? Using their own experiences, they shared how they would reassure patients about the robustness of treatments, largely through established government-owned information platforms, regulation and standards (fig. 4).

Figure 4: Speculative prototyping: participants explored possible public perceptions of PMF (PNs on left) and discussed how they might allay peoples' fears (PN on right)

How co-design affords mutual understanding

As discussed previously, service design takes a different approach to the central challenge of PMF - indeed any novel biotechnology - in enabling lay-understanding and acceptance, than conventional methods used by the sciences and social sciences. Central to this approach are co-design tools and methods which can reveal hidden values and enable dialogue between diverse stakeholders.

Although analysis and theory building is ongoing, the case summary provides preliminary evidence for how the approach has already laid foundations of building mutual understanding, by:

- challenging or adding detail to the assumptions of the technology developers, for example in expanding upon the stakeholder ecosystem of 'the hospital' and revealing important additional care and coordination roles in pharmaceutical provision;

- revealing the values of the technology to stakeholders which were hidden from the scientific partners prior to the workshop, for example the importance of 'ease of use' to the specialist nurses in particular and the 'novelty' of trying a new product for patients;

- translating and facilitating, in the workshop preparation - for example, translating the codified technology into understandable narratives around pharmaceutical production, and during the workshop - and by facilitating mindset shifts from the micro frame of the clinical context to the macro context of the populous view.

This paper aimed to demonstrate how design researchers can resist the conventional roles for design in service of 'science communication', by facilitating emergent solutions, not simply providing them (Fisher & Gamman 2018:215; Aguirre et al 2017) and creating open-ended co-designed interpretations of stakeholder experiences and values (Mattelmaåki, Brandt & Vaajakallio 2011) in relation to novel biotechnologies.

The early results show that stakeholder engagement in healthcare is often challenging, opportunistic and therefore imperfect. However, service designers perhaps more than other fields of research, employ exploratory, sensemaking, co-design methods which can be adapted to the changing situation as it evolves and as the research scenario unfolds.

The value of our approach for the project is not only that we can communicate these insights back to the scientific partners, but also that it provides us with possible mechanisms or narratives for challenging peoples' fears of the technology.

A shortcoming perhaps of this type of multi-disciplinary project is that there are limitations on design's role and the subsequent research design. Invited into the fold, we - the design researchers - are not leading the show, we are guests and must tread carefully along the path of expected design roles. This poses challenges for the service design approach, particularly in a project that is organised on a science and technology innovation premise, defined by scientific conventions. However, we can be the 'tricksters' (Fisher & Gamman 2019) working with the co-design tools and methods at our disposal to reveal hidden value and meaning both of the technologies and of design's role.

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