

'DEFEND, DEFEND, DEFEND': women's HIV health activism, embodied feminist performance-making and radical kindness

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ABSTRACT

This article shares the learning from our project, *Positively Past, Positively Present* (PPPP), which started in 2022 in partnership with Positively UK, formerly known as Positively Women, a UK HIV support and advocacy organisation. The PPPP project is an archival, oral herstory project which focuses on capturing the herstories and experiences of women and others who were part of Positively Women. Our aim was to consolidate these women's herstories and by sharing this knowledge prevent these extraordinary narratives from being invisibilised again. In this article we articulate how our use of embodied feminist performance-making in health activism can help to nurture the roots and interconnections of these knowledges, and in doing so, 'DEFEND' the loss of these stories.

INTRODUCTION

Through *Positively Past, Positively Present* (PPPP), an archival herstory project marking the 35-year history of Positively UK¹, a peer-led HIV support and advocacy charity, this article discusses the role that embodied feminist performance-making can play within women's HIV activism. The project was spearheaded by Silvia Petretti (current CEO of Positively UK, formerly a service user of Positively Women) and key members of staff of Positively UK, and artist academics, Katharine Low, Chuck Blue Lowry and Maryam Shaharuddin and focused on capturing the herstories and experiences of women and others who were part of Positively UK which was formerly known as Positively Women.

At the heart of our approach was the desire to facilitate space and amplify the voices of marginalised women whose herstories of living with HIV had been 'neglected' and hidden, acknowledging that distinct modes of knowing had been overlooked, particularly in terms of the body as a maker of knowledge. In this way embodied knowledge, that is to say the validation of the body as a key site of knowledge formation, forms a cornerstone of our practice as a counter to structural and epistemic injustice (c.f. Low 2025). Our aim was to consolidate these herstories and by sharing this knowledge prevent these extraordinary narratives from being lost. In this article we articulate how our use of embodied feminist performance-making in health activism can help to nurture the roots and interconnections of these knowledges, and in doing so, 'DEFEND' the loss of these stories. We take inspiration from the words of Elisabeth Crafer, a former

CEO of Positively Women (1998–2011), who argues, 'everything that we have won as women – DEFEND, DEFEND, DEFEND, because we will have to do it, always' (Crafer 2024). It is useful to flag that we deliberately use the word *knowledges* rather than knowledge in this article as a counter to the reductive singular ownership of knowledge and to capture the multiplicity of voices and experiences this project celebrates.

To begin, the work of Positively Women, the establishment of the PPPP project and our consideration of sites of knowledge and knowledge-making articulating our use of embodied feminist performance-making in health activism is contextualised. We then explore what emerges from the practice of engaging with and performing the archive, specifically exploring what emerged during the recording of the podcasts, the creative engagements with the archive materials of Positively Women and the resulting performance and the creation of a short film based on one of the founders of Positively Women's words: 'Rebelliousness was born in me' (1992, 3).

Positively Women (now Positively UK)

Positive Women are NOT just sad women or famous people; they are a hundred other things besides being HIV positive; they are all living with HIV; they could be anyone – you or your neighbour or your sister or your lover (O'Sullivan and Thomson 1996, viii).

Established at the height of the AIDS pandemic in the UK in 1987, with Sheila Gilchrist, Jayne Davies, Kate Thomson and Caroline Guinness as a core group and supported by other women, Positively Women offered a weekly space and a telephone line for women living with HIV. This was partly in a reaction to the gendered and homophobic perception of HIV/AIDS at the time, where there were no services specifically for women living with HIV; women were 'invisible' in most research and policy-making undertaken at the time (c.f. Scharf 1996, 165). Sheila opens the account of her journey of living with HIV with these words: 'Rebelliousness was born in me' (1992, 3). Sheila's rebelliousness led her, with other women activists living with HIV, to establish Positively Women in 1987. The organisation swiftly became a site of support, recovery and change for innumerable women living with HIV in London and the UK. In the words of Fiona² who accessed Positively Women at the start of her diagnosis: '... it is thanks to all those women that my having to deal with HIV was easier than it would



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have been, [and] for other women who didn't initially access their services, [Positively Women] was always there, waiting for them with open arms when they decided to. So, thank you Sheila' (Fiona 2024).

Thus, Positively Women began as a peer support and knowledge-sharing organisation, sharing peer-learning and peer-advocacy. At the core of the organisation is an ethos of the value and importance of peer support, specifically that individuals living with HIV need to be 'meaningfully involved' in any decision-making advocacy (Positively 2024). In 2011, Positively Women rebranded as Positively UK and shifted their focus to include everyone living with HIV to better reflect the need for integrated advocacy and peer support for all people living with HIV across the UK. Although living with HIV can be a gendered experience affecting individuals differently due to biological as well as socioeconomic factors, Positively UK has led the way in championing for and creating viable peer support structures for all people living with HIV. Over 85% of their staff team live with HIV (Positively 2024).

While Positively UK continues to champion and advocate for people living with HIV, the funding climate becomes more and more precarious and the acknowledgement of the herstories and successes all that Positively UK has achieved is being lost. We are on the precipice of losing this herstory mainly as a result of what Fricker (2007) terms epistemic injustice where marginalised individuals' ideas are excluded, silenced or as in the case of women living with HIV, overlooked due to a wider society's systematic dismissal of the worth of certain knowledges. The invisibilisation is multifaceted and for women living with HIV, who often experience being excluded, overlooked and vulnerabilised, particularly in a medical care setting (Namiba *et al* 2022), this forms part of a wider exclusion of women's bodies from society.

Yet, Sheila's story, the stories of the women who started Positively Women and of the many women who live with HIV are no longer shared or acknowledged. In essence our project is an archival and performance-based project to ensure that these herstories are preserved. Sue O'Sullivan, one of editors of the book, *Positively Women: Living with AIDS*³ (1992), notes:

I am obsessed with archiving material. I just can't bear the idea that material and stuff that comes from your lives, my life, our different periods of concern, might be, what we used to call, 'hidden from history' again (O'Sullivan 2024).

Speaking at the screening of *Sheila's Story* (Lowry 2024), a short film based on Sheila's memoir, Sue extends her point about women's herstories again being lost. Sue notes how she borrowed Sheila Rowbotham's term 'hidden from history', which is based on the account of the Women's Liberation Movement yet remains apt for the story of women living with HIV today. Sue argues, 'we learn from history. If we don't have those roots, we have lost a part of ourselves because we are all a part of that history even if we haven't been born when that happened' (2024). We already know so little about women's experiences of living with HIV and we cannot afford for these stories to be "hidden from history" again'. This is particularly pertinent when we consider the wider cultural response to HIV, which historically has often highlighted the gay male experience (see Campbell, 2019 and Schulman 2022). Women with HIV have never been prioritised and unsurprisingly, in 2020 the HIV Commission found that across the UK, women, more often than not, experience late diagnosis (over 50%) and do not share the same 'best HIV outcomes' as other groups and, most significantly of all, are not

experiencing similar parity in decreases in HIV infection (HIV Commission 2020).

The genesis of the PPPP project: celebrating other ways of knowing

In 2021, Kat Low and Maryam Shaharuddin facilitated open access creative story-telling and sewing workshops to accompany the thirtieth anniversary exhibition of the UK AIDS Memorial Quilt developing a new panel for the Quilt commemorating the lives lost since the last iteration of the quilt in 1991.⁴ During the quilt-making workshops, Silvia Petretti (Positively UK CEO) and Angelina Namiba, a leading HIV activist, came to sew a panel to commemorate the lives of Leigh Neil, Sheila Gilchrest and Jayne Davies. Through discussions that day and following further conversations with Silvia, we successfully applied for Knowledge Exchange funding from the Royal Central School of Speech and Drama (RCSSD) to develop the PPPP project, to commemorate the thirty-fifth anniversary of the establishment of Positively Women. One of our main drivers was to facilitate a dedicated space to listen to other women's knowledges of living well with HIV⁵ and acknowledge other ways of knowing.

The dominance of the male-identifying queer or LGBTQIA+ experience is not hard to find, but a woman's narrative—herstory—is notably absent.⁶ In essence, this project is about making space for different ways of knowing and as an archive project about ways of holding and sharing these knowledges for future generations. Our practice is underpinned by the principle that there are different ways of knowing and ways of gathering, paying attention to and sharing these knowledges.

Here we are informed by Donna Haraway's thesis on materiality and the telling of stories where she argues: 'It matters what matters we use to think other matters with; it matters what stories we tell to tell other stories [...] It matters what stories make worlds, what worlds make stories' (Haraway 2016, 12), because in doing so new worlds are imagined and built. This is particularly relevant for women living with HIV as alternative ways to sharing knowledges in spaces where the multiplicity and the complexity of these women's lives and lived experiences can be shared. For us, performance-making, creative engagements and archival endeavours enable a counter to the existing cultural representations and societal understandings of what it means to be a woman living with HIV.

We wanted to consider what we could learn from this and what knowledge would emerge. Accordingly, we developed and designed a project with four performance-making strands: podcasts, workshops, a performance and a film. The podcasts focused on recording interviews with key activists, volunteers and allies who had been part of, or involved with, Positively Women at the start and throughout the 35 years of the organisation, acknowledging and recounting its journey to the organisation it is today. In the podcast and the workshops and performance that followed, we drew attention to the herstories and experiences that were held in the archives at the London Metropolitan Archives (LMA) and at the Bishopsgate's Library. These resources, materials and archives were filled with photographs, herstories, a memorial book, and organising strategies and information pamphlets. Accordingly, we devised a series of eight creative workshops at the LMA whereby women who attended the monthly women's support group could take part in activities exploring the archives; to sit with that herstory and to consider where else, and what next.

We began the PPPP project with the participatory applied theatre-based workshops (which ran between May and

November 2022); the outcomes and ideas discussed within those workshops then informed the performance we developed for the thirty-fifth anniversary celebrations of Positively Women on 23 November 2022. Concurrently during this period in September 2022, the Podcast series began recording (recordings concluded in the summer of 2024) and knowledges from the interviews were fed into the workshops and the performance in 2022. The final part of the project included filming a short film of Sheila's story, based on her words, which had its first screening on International Women's Day on 8 March 2024, to an invited audience hosted by King's College London before premiering at the twenty-fifth International AIDS Conference in Munich in July 2024.

A note on embodied feminist performance-making

For us, embodied feminist performance-making is a recognition of the work that happens in the creative space, and how this holding of the space structures the performance-making. The manner in which the space is set up, as equitable, open and responsive, underpins the creative process so that different individual understandings of health can emerge, resulting in new forms of knowledge. As Low has argued elsewhere, '[t]he doing of performance sets up a material space for these conversations, for different and counter-stories and experiences to be experienced and shared in a collective space' (2025/forthcoming). From such shared understanding, critiques of the medical encounter with HIV and the public reception of HIV can be dismantled.

The various components of the PPPP project, from traditional theatre-making to podcasts were understood under the umbrella term performance-making. The workshops were rooted in applied and socially engaged approaches to theatre-making, and the manner of facilitation in those workshops was also extended into how the interviews for the podcast were set up and conducted. Finally the curating, devising and filming of Sheila's story, an act of performance itself, was held through a radically kind approach and care, which is discussed shortly. All of these different creative approaches to capturing and drawing attention to the stories in Positively Women enabled us to engage in different forms of knowledge-making that were embodied and experienced. Here we draw on Sara Ahmed's notion of 'feelings of structure' (2018) and how these structures are 'impressed upon' women's bodies through feelings (2018, 62). These impressions from the felt experiences leave marks, even if they are not visible. Building on this understanding, the performance-making is a means of investigating, critiquing and considering these experiences and taking that knowledge into the everyday lived experience of the participants. In the making of these performances, the women are telling different stories, yet these stories have materiality because they take up space both by the attention paid to them and by the impressions these narratives leave on the listeners. Through these new knowledges connections are made which recognise the multiplicity of forms of knowing about what it means to live with HIV as a woman.

Our shared approach to performance-making and socially engaged theatre-making is embodied and feminist-led because it pays attention to small, often, overlooked moments. This includes making space to explore, hear and listen, examine and address particular hidden occurrences. In this way it is rooted in Low's concept of *apertures of possibilities*, of noticing the small, seemingly inconsequential event (Low 2020). In that moment of looking, the work we are doing is noticing various different things, including spotlighting and drawing attention to marginalised female lived experience. The work itself is holistic; in our

practice, women living with HIV are recognised in their multiplicity of being—there is no single narrative of who they are; they are not solely perceived in terms of their viral load and they are not 'sad' women. And, finally, this approach enables a dismantling of perceptions and patriarchal reductive views of what it means to live with HIV. Through doing the work, there are opportunities and means to have lived experiences validated and celebrated.

Fundamentally, embodied feminist performance-making makes the viscerality of health tangible, so that we are able to consider, explore and critique the health experience and acknowledge the wider societal and biological factors and implications. In the sitting with the oral herstories and then making of performances informed by these, knowledges arise and new forms of knowledges are produced. This adds to a wider cultural understanding and interpretation of what it means to be a woman living with HIV. In doing so, particular narratives of what it means to be HIV-positive are not only challenged, they are interrupted. In this way, the making of creative artefacts and works allows for the ephemeral to be made tangible.

Radical kindness as a methodology: a note from Kat

As an established practitioner-researcher in arts and health, I (Kat) have had the great privilege of collaborating with Positively UK since 2016. As a socially engaged theatre maker, my focus is on employing creative methodologies and approaches where space is taken up to be heard and considered and through this sharing celebrate new knowledges and paying attention to the alternative herstories. My practice is deeply informed by the work of Pumla Dineo Gqola, a South African feminist who argues, 'It is never enough to simply illustrate how patriarchy works in order to understand it. The feminist imperative is to think against it, strategise against it, and consistently work to destroy it' (Gqola 2021, 14). Accordingly, my way of working is informed by a feminist principle of dismantling patriarchal conceptions and societal expectations of health and what it means to be a woman; specifically in this context, as a means through which we can challenge patriarchal perspectives of what it means to live with HIV as a woman. Thus my practice invites a space to explore and note what is paid attention to (ie, here the overlooking of these women's lived experiences) and the manner in which we pay attention (how we approach the work).

Informed by Gqola's principle, my practice focuses on holding space through a methodology of radical kindness, an approach to practice which I describe as reclaiming 'the idea of kindness and care not as "un-heft-like," "feminine" qualities with overtones of patriarchal, matriarchal and colonial biases, but a deliberate look at the radical potential inherent in small acts of kindness.' (Low 2021, 170). As I discuss there are four dimensions to radical kindness:

firstly, it resists perceptions of a "vulnerable," stigmatised body; secondly, it upholds the potential that lies in a consideration of the quotidian and quiet advocacy; thirdly, it foregrounds the role of the facilitator in supporting the workshop and the care that takes place within those spaces; and, finally it is an observation of the potential outcomes which can emerge even when these may be subtle. (Low 2021, 170).

In practice radical kindness involves non-hierarchical approaches and ways of engaging, co-collaborative making, and kind and gentle holding of a space and, for me, facilitating and practising in a radically kind manner, enables space for individuals to come as they please and to be present and engage in

whatever they feel able to. Individuals, in this case, most often women and those who identify as women, are invited to take part in an artistic process which regularly dismantles the traditional hierarchical structure of the performance-making space, such as one sole ‘authoritative’ director/facilitator, strict meeting and gathering times and specific roles within the work. We hold a flexible space; no one is chastised for being late and individuals do not have to actively ‘take part’. Instead they can choose to sit and observe and eat the shared food, indeed engage or watch according to their want and desire. Accordingly, the offer of the activities and the exercises themselves are adaptable and responsive to the participation level on the day. By embodying a radical kindness methodology, I am holding the space in a similar manner to that of how the peer support spaces were facilitated at Positively Women: it allows for a collective holding of individuals and the community in the space, which allows us to go deeper, make connections and work equitably with a lot of flex and flow between so-called participant and facilitator.⁷ Thus in dismantling the hierarchical nature of more traditional approaches to performance-making practice, radical kindness invites a space of blurred lines of participant and facilitator allowing multiplicity of interwoven narratives to be heard.

In addition, the radical kindness methodology was the ethos which surrounded the making, curating and organising of the PPPP project. This approach is about offering an invitation to work with kindness and flexibility and non-patronising care to all those involved in the project. This stance is about making space for caring responsibilities in all their multiple forms, workloads and precarious contracts, bereavement, staying aligned with the sisterhood ethos evident in Positively Woman, and working with care and sensitivity to best portray the stories, lived experiences and herstories shared with us during the entirety of the project.

The applied theatre⁸ methodology of radical kindness is rooted in my theory of *apertures of possibility*, which is an invitation to both notice and acknowledge the small moments, the seemingly inconsequential moments, that occur in participatory creative-based practices (Low 2020). Although as an individual moment, this moment may not appear significant, but when viewed as a collection of other ‘small somethings’, they are meaningful and quietly significant. Through the thinking around *apertures of possibility*, I share the invitation to take a closer look at the effect of these unintended moments in socially engaged theatre practices, for it is in these moments, that we might not necessarily acknowledge or consider as having import, that we are able to see and trace significant affects and affectual responses and new knowledges emerging. Within the field of health-based projects, performance-making enables deeper explorations of people’s health needs and allows new knowledges to be shared which can in turn help dismantle existing understandings of the predominant gendered experience of living with HIV. For example, as we will discuss shortly—this is seen in the creation of performed scenes built on women’s experiences of meeting their GPs, for those in the audience, listening and reacting, understandings of the marginalisation and dismissal experienced by the performers is shared.

My work with Positively Women is emboldened by a synergy in our approach: we both hold a deep commitment to celebrate and hold spaces for women’s health experiences. From its genesis, Positively Women’s focus has been about knowledge production and eradicating shame. In the words of Julie Reynolds, a former member of staff:

shame breeds with secrecy and with hiding and with not being able to be open and, this [Positively Women] was a place where women

could come and be themselves, and learn by talking to others, and have the space to hear their own stories and to voice their own stories, and to take power in the shared stories of each other (Reynolds 2024).

For all those at Positively Women, now known as Positively UK, their focus has always been about recognising and calling attention to what women and their bodies know. In this way, Positively Women has always been about knowledge production, and this is where our practices interconnect; through performance-making and exploration, knowledge is heard and shared. Together, our practice has been about amplifying and drawing attention to the hidden herstory of the HIV pandemic, namely women’s overlooked experiences of living with HIV and their ongoing health needs to see and value what else is happening.

In the sections which follow we explore these ideas, beginning with the creative workshops and the resulting performance in November 2023, before moving to the *Positively Present, Positively Past* podcast series and the reception of *Sheila’s Story*, the film we developed.

Performing...

Dear future, we look to you full of hope and pride. We will bring what we have learnt from our experiences in the past and the present to unapologetically take up space and hold those spaces too. Scene from the performance, 23 November 2022

Informed by embodied feminist pedagogies (see Coetzee 2018; Magnet *et al* 2014) to performance-making and radical kindness, we worked in a collective manner, developing workshops and themes with colleagues from Positively UK, Kat and Maryam as facilitators, and with applied theatre students from RCSSD. In our initial planning of our approaches to performing the archived work, Kat and Maryam sat with the materials to collate, order and identify threads and themes. Then, through discussions with Silvia and Sarah Fraser, another colleague from Positively UK, we created a plan for several workshops, some co-planned and co-delivered with our students, and others planned and delivered by ourselves. There exists an understandable impulse to lean towards the upbeat and the celebratory, a ‘look at how extraordinary’ gaze and to celebrate those fierce first leaders. While it is important to celebrate and call attention to this herstory, we also need to acknowledge both the ‘shadow and the light’⁹ of these herstories. Significantly guided by Positively UK, our intent was to ensure that we did not fall into a form of ‘toxic positivity’; a reflecting back on the past as a means of celebrating what was learnt without acknowledging the hardships, the grief, the anger and the loss experienced at the time. This steer was a constant reminder for us working with hidden herstories that are not our own. Sarah introduced the work of the Buddhist teacher Jack Kornfield into our discussions and his offer of honouring grief, where he suggests: ‘When we grieve we allow ourselves to feel the truth of our pain, the measure of betrayal or tragedy in our life. By our willingness to mourn, we slowly acknowledge, integrate, and accept the truth of our losses. [...] It takes courage to grieve, to honor the pain we carry’ (Kornfield 2022). Taking time to acknowledge what has been lost, alongside what has been gained, to honour this process thus formed the cornerstone of each workshop.

In sitting with the materials, we acknowledge what it has meant for participants who are part of this herstory to hear the herstory of the work and establishment of Positively Women and place this in a broader collective herstory of what it means

to live with HIV. Indeed, in the words of one of our narrators who closed the performance: ‘*Dear future, we look to you full of hope and pride. We will bring what we have learnt from our experiences in the past and the present to unapologetically take up space and hold those spaces too*’ (Narrator 3, *Dear Past, Dear Present, Dear Future*, 2022).

The first workshops explored specific themes and materials and the archives offered an extraordinary collection of material herstory and artefacts. There is a thrill in sitting with these wide-ranging materials, including all the back copies of the *Positively Women* magazine (at the time the only magazine for women living with HIV, written by women living with HIV freely available) (GP Online 2007), photographs of marches and protests, and key publications that *Positively Women* wrote or contributed to, in particular the whole series on ‘Your Rights in a World which has HIV’ covering insurance, travel, housing and healthcare.¹⁰ Thus for each workshop, we drew on curated collections of artefacts to explore several themes, which included: Your Rights: How have they changed?, Invisibility and Hypervisibility, Wellness, Activism and Politics, Blame and Shame, the Women who Come Before (where we listened to verbatim performances of extracts from the podcast interviews), Mothers and Loneliness.

Each workshop was attended by between 12 to 18 women, some repeat attendees, others coming once or twice. The women who attended were invited through the Women’s Group coordinator (Neo) at *Positively UK*. There was a wide range of women with varying personal situations and concerns from immigration status to the experiences of health inequities. Some participants had very recent HIV diagnoses, others had been part of *Positively Women/UK* for decades. For some, this was their first in-person interaction with *Positively UK* since the COVID-19 lockdowns. All participants were reimbursed their travel expenses and given an honorarium; after each workshop we gathered to eat together. In each workshop we focused on a specific theme, working in small groups to explore and respond to chosen artefacts from the archives. Their responses formed the starting point of all the creative activities, including developing group and individual poems, zine-making, making campaign badges, the creation of scenes and responses to archival material or key extracts from the podcasts as they were being recorded, developing new pamphlets for the twenty-first century (‘the new age of HIV’), creating soundscapes and monologues developed out of a letter-writing exercise to their past, present and future selves.

The creative collaging involved participants designing and developing campaign badges that demonstrated their individual activism goals and ambitions, in response to the work that past *Positively UK* activists undertook. Here we employed a visual art-making technique to capture the histories and knowledges from the discussions in the room. This consolidated key ideas into slogans and testaments to live by, which were performed into action as the participants left the room, wearing their protest pins and badges. This in turn informed the shadow puppetry workshops, where the women embodied and then enacted their lived experiences of living with HIV into a stylised movement sequence. This non-verbal telling allowed their bodies to share impressions viscerally by not relying on words as tools for communicating, thus celebrating different forms of knowledge-making and processing. This in turn led to the development of a scene for the final performance for the anniversary event.

Similarly, in response to photoshoots that the key staff members at *Positively UK* took part in the early 2000s and the published headshots that Mario Testino took of *Positively UK* members in the 1990s, the women recounted the women most inspirational to them. By sharing examples of their approaches,

Box 1 Extracts from Letters to Past, Present and Future Selves—performed at the November 2022 event.

Dear Past:

When you were 32 it was impossible to think of having a future. With ‘maybe only 6 months’ to live. All you could do was to live as well as you could. But look at you now, almost 63!

Dear Present:

Dear Me,
I feel like a normal person now.
Take my one tablet and move on with my life.

Dear Future:

Dear future, I’m looking to do everything I couldn’t in the past. Time
I have wasted in the past thinking I wasn’t going to make it. Travelling. Eating out with friends. Making new friends. Getting out of the shell I was hiding. Looking at myself in the mirror and love myself again.

care and activist practices, the participants selected an element of that person, or the whole person, and captured their impressions through a portrait painting exercise. This placed the female experience of HIV at the centre of the artistic engagement, allowing sensitive and evocative memories to be heard and acknowledged, and importantly taking the space to celebrate and mourn these key women in the participants’ lives. These portraits then framed the walls around the performance space for the November 2022 event, bringing those key individuals into the space and recognising the impact they have had on the participants in the room thus making tangible both the viscerality of health and lived experiences of those who had come before.

All of these workshops fed into the final production, where key elements and ideas explored through the participatory workshops were developed into content for the play. So, for example, extracts from the letter-writing exercise were developed into a spoken word piece and is shared here (see [box 1](#)):

In these extracts, we can read a countering of the single narrative of what it means to live with HIV but also of the experience and privilege of growing old with HIV, when so many others were not able to do so, and of the challenge of living in the UK post-COVID. The co-created poems, included below (see [table 1](#)), *We Are NOT Sad Women*, *We Are NOT Sad Mothers* and the poem about peer support, *I Am, Because You Are!*, are two beautiful examples of a collectively curated recollection and account of the process of sitting with the materials and debating and considering shared learning and experiences.

The creation and making and knowledge exchange that occurred through the workshops then informed the content of the performance in November 2022, performed in three parts: *Dear Past*, *Dear Present* and *Dear Future*, where the creations from the workshops were displayed and excerpts from monologues and scenes were shared. Here we have chosen to include the scene developed in response to the women’s experiences of attempting to access care at their GP surgery (see [box 2](#)). As you read through the scene, their experiences of being ‘medicalised’ is screamingly apparent—they share how often they are reduced

Table 1 Co-created poems, shared at the November 2022 event

We Are NOT Sad Women, We Are NOT Sad Mothers <i>created by the performance group October 2022</i>	I Am, Because You Are! <i>created by the performance group October 2022</i>
Living with HIV can be challenging, but it doesn't define me, so I am not sad.	Sitting on a comfy sofa in front of a roaring fire. My mother who held me in my first home. Her womb.
Positive mindset keeps me strong. Strong I have my children and I am surrounded with my lovely friends. The peoples in the group.	I am a wonderful mother. Very supportive She was warm and empathetic. Believed in me.
Smiles.	
I am set on a mission. I have my god. I can breastfeed my son because my viral load is BRILLIANT. Achievement.	I love you. You inspired me. "it is going to be ok" she is my sister, my everything.
Living with HIV can be challenging, but it doesn't define us, so we are not sad. Success,	What is a sister? Strong, powerful and beautiful. Sister, come together.
Breastfeeding motivates me to always use my drugs. I never missed using my drugs.	Understanding the need to be there for each other. Stronger.
Empowering women is my goal.	I found courage.
Lovely.	I am here because you gave me hope.
And here I am still, unapologetic looking beautiful and energetic.	I am, because you are!

in the medical encounter and their refusal to hold such a position anymore.

The development of this scene became a focus in the workshops before the performance, leading to much discussion as to what it is about being a woman that makes things harder in terms of being listened to and heard, specifically in terms of HIV medication and interactions with other medications for women. At the time new studies vindicated women's experiences, noting how often their reports of weight gain while on specific HIV medication were dismissed and reframed as being due to poor diet choices (Cohen 2019; Kanters *et al* 2022; Venter *et al* 2019, 2022). In the final version of the scene, the women were keen to demonstrate how listening to each other's experiences with seeking medical care over the different workshops and learning from each other had emboldened them to be more forthright and take up space in their interactions. This was clear when they chose to close the scene by choosing Neo's statement where she refutes the doctor's diagnosis.

What this scene shares with us is a deeply felt and multiple experience of encounters with a particular medical gaze and the lack of understanding that results in marginalisation. The women share their experience of how it feels to live in a gendered, medicalised body and then how they are refuting this gaze and reading. Indeed, one of the outcomes of this exercise and the resulting scene we developed was a pooling of starter phrases that the women could use to start conversations with

Box 2 Co-devised scene about shared experiences at GP surgeries, performed at the November 2022 event.**Scene 1: GP Surgery:**

Chairs are set out in rows to look like a waiting room of a GP surgery, the women are sat within the audience. Scene begins with the group gesturing to look like doctors—the cues for this is led by I. They all look over their shoulder to the right. They then put gloves on. They then put their hands out in front of them. They then type on a computer. They then turn and lean to the right like a doctor looking at a patient—this is the cue for the first line.

A: How can I help you? (the group repeats the line, then gestures typing on a laptop, and then look back to the right at the patient—this is the cue for the next line)

A: Oh, are you HIV Positive? (the group then repeats the line)

C: How do you treat a woman who is HIV Positive and also has the menopause? (pause for a beat, then group raises hands and makes a frustrated shout.)

J: Hi Doctor, why is it so difficult to get an appointment at this surgery? You tell me to call at 8am every day and I am just fed up.

K: Hello Doctor (pause) I am good thank you, how are you? (pause) I have been having problems with my legs and my feet. It burns. Will you be able to do something about it? (pause) Thank you doctor, that is so helpful. (Group does a relieved sigh and smiles)

G: HIV and anxiety makes me feel sad. (Group looks around the room awkwardly)

F: Good morning Doctor Smith (pseudonym), why is it that the blood test sample I collected had my HIV status on it? (pause) Oh so the person who wrote it is new? (pause) And this is not the policy of the surgery? (pause) Thank you for giving me a new one. (Group shakes hands with people next to them)

B: (talking to a doctor) Hello, Doctor, it's me again. (talking to the audience) My doctor is good. She is good for me. She refers me quickly. But when she is not there, the other doctors are always asking me if I am HIV positive...

All: Positive? Positive? (this repeats until Abe cuts it off with the next line)

B: ...and I am tired of it.

N: No, (everyone looks at Neo) I don't think this has to do with my HIV status. I have been taking my medication for the last 10 years. I am undetectable. It's linked to my new medication I'm taking. I would like you to look at it in more detail. (Group clicks their fingers).

their GPs and to exert their right to dignified and informed treatment. Through the performance-making methodology the women have a space in which to explore and critique their health experiences, bringing different knowledges and experiences into the space and in turn sharing those knowledges and thus beginning to dismantle perceptions of what it means as a woman to live with HIV. Here a methodology of kindness results in the women taking the sharing of sensitive and intimate encounters to embolden them to advocate for themselves in the medical spheres where hitherto they have been marginalised and not understood.

The action of embodied feminist performance-making was key here as it enabled, through the workshop space and the sitting with materials, shared learning with the women describing their experiences in response to the stimuli from the archival

materials, exploring how things have (or have not) changed, exclaiming with delight at old photos of themselves and their friends and colleagues, honouring those who are no longer with us. There is a significant power in being seen and heard and actively contributing to this knowledge collection, this gathering together to share, strengthen and build on this collectively held herstory. Fundamentally, women in the workshops and performance share knowledge and learn from each other. Through the public performance, they share that knowledge with a wider audience, dismantling and challenging views and making ideas of HIV and women visceral and tangible. They have brought herstory alive and have made connections and learnt from each other. One of the most marked outcomes for us was noting how attending the workshops in 2022 was one of the first public activities for many of the women since COVID, where they were often isolated due to being deemed 'at risk' and told to 'shield' by the government (BHIVA 2020).

Alongside this, the conversations that we had have raised key questions about stigma and self-stigma. With conclusions emerging that called for a re-educating of society, whereby 'Society needs to be educated to destigmatise all the negative connotations and outlook that they have for women living with HIV' (Anon 2022) and a fair argument for the general public to stop putting the onus on people living with HIV to teach them about what HIV means and go and find the knowledge themselves. A call for society, in the words of a current project with Positively UK, 'to LISTEN LOUDER'.¹¹ Here, the podcasts form part of this process, an invitation to hear more and to, hopefully, listen louder. Indeed, the podcasts are an extension of our approach to embodied feminist making—whereby the taking of space to recall and tell these stories is a step towards dismantling existing perceptions or revealing hidden accounts.

Recording... the *Positively Present, Positively Past* Podcast series

We need to tell those stories because it is through those stories that we know who we are... Silvia Petretti (8 March 2024).

As we planned our podcast series in late 2021, existing podcasts around living with HIV focused on the male experience of living with HIV or of young people's experiences.¹² Yet, the women's experience of living with HIV has never been the focus of mainstream discussion of HIV, it remains neglected in cultural production and sharing. For example, the 2021 series *It's A Sin* was celebrated as the first TV to offer a perspective of English HIV/AIDS activism and an account of what it was like to live through the emergence of AIDS in the 1980s' London and beyond (Severs 2021). Once again the female experience was overlooked here, with women taking up the 'caring' roles through the characters of nurse, mother or friend.¹³

This herstory played a key part in the development of our podcast series, concerned as we were with offering the broadest possible account of the development of the organisation while also paying attention to the diversity of stories, routes and reasons why women contracted HIV and were seeking advice and support during their diagnosis. We felt there was an important drive to offer a more nuanced account of what it means to be a woman living with HIV, making space for the uncomfortable, so-called disobedient women's experiences, those women perceived to be disobedient for contracting HIV through drug use, sex work and/or being in prison. Positively UK wanted to make hearing these stories more accessible and crucially, for the committee who decided and approached people to be interviewed, our drive was twofold: to capture as many of the

herstories and stories from the early days of the organisation and, second, to offer a disruption of a presumed narrative of what it means to be a woman living with HIV. The development of this project, coming off the back of the recent death of Leigh Neil,¹⁴ coupled with the difficulties of engaging with individuals with compromised immune systems during COVID-19, gave a sense of urgency to capturing many of the stories.

Accordingly, we have offered accounts of many different kinds of women, of many different kinds of experiences, about honouring the grief, fear, anger and complexity of feelings that our interviewees have experienced. To that effect, we captured the development of the organisation, exploring the work of Sheila, Jayne Davies, Kate and Caroline in an interview with Caroline Guinness and Kate Thomson.¹⁵ We then charted the development of the International Community of Women Living with HIV¹⁶ informed by Positively Women's practices by speaking with Jo Manchester,¹⁷ and Carolyn Williams and Fiona Pettitt.¹⁸ Focusing on the experience of women, we broadened the discussion by offering insights from Cinzia Milesi, one of the first prison workers at Positively Women and Sophie Strachan, who went on to become a Prison Worker for Positively Women following her experience in prison and receiving peer support from Maria.¹⁹ Sophie reflected on the process, describing how the women who came before her 'Walked the path ahead of me to follow in their footsteps', leading her into her advocacy work today as CEO of the Sophia Forum. This repeated leitmotif of sisterhood, women making and holding space for other women becomes a recurring theme through many of the podcasts. For example, we see this in Angelina Namiba and Rebecca Mbewe's interview,²⁰ where they speak of the support and friendships developed, as they discuss navigating motherhood and developing careers.

Fundamentally, the podcast series has been about offering multiple accounts of herstories and adding and complicating the collective narrative. This is particularly apt when we consider the role of African women and HIV. Often at the time perceived as victims or illegal claimants, our interview with Beatrice Osoro,²¹ who first started working with Positively Women as a volunteer, spoke about the contribution of African women to the HIV sector and of the impact of Positively Women's development of services for African women. This podcast draws attention to the learning and contributions that women coming from the continent of Africa have provided to the UK's response to HIV, which again complicates the single narrative of 'refugee women living with HIV'.²² Alongside this we have drawn together many accounts from women about their pregnancy and motherhood journeys, with Janine McGregor Read speaking to her refusal to accept the medical thinking in the 1990s, that it was 'irresponsible for someone with HIV to get pregnant,' arguing instead: 'To put a woman in a position where she can't think for herself is insulting.'²³ Today, Janine works at Homerton Hospital supporting pregnant women to ensure women don't have to go through what she did in the 1990s.

Our podcasts also include interviews with key HIV clinicians including with: Professor Jane Anderson,²⁴ who called for more attention to be paid to women's experiences of HIV while working on the AIDS wards at the start of the pandemic; Dr Shema Tariq and Dr Rageshiri Dhairyawan,²⁵ two exceptional HIV consultants who campaigned, and still campaign for more attention to be paid to the gendered nature of HIV and for women to have more space in HIV research. Each interview closed on the same question: 'What are you bringing from your past into your future?' The responses have been as myriad as the interviewees themselves, but each answer, each idea prompts

another thought or connection, and rightfully takes up space in the collective narrative. These podcasts were also crucial to the PPPP project as they informed content for the creative workshops where we worked through the archives at the LMA. We closed our series with our eighteenth podcast interviewing Malika Cholway and Chiesa Musonda,²⁶ two extraordinary young people who grew up on the Positively Women premises at Sebastian Street.

Filming... *Sheila's Story*

No one here would have met if it wasn't for Sheila

(Donna Riddington at the screening of *Sheila's Story* on 8 March 2024).

As we come to discuss the final outcome of our project, the film of Sheila's life, it becomes apparent that Sheila is a 'mother tree'. Here we are informed by Suzanne Simard's book, *Finding the Mother Tree* (2021), which recounts her life as a forester and scientist in the forests of British Columbia, Canada. Through her memoir, she shares her thesis that forests are social and connected in nature, whereby older (elder) trees communicate and share knowledge through a mycorrhizal network (made up of mycelial threads). Simard calls these elders, 'mother trees' and describes how they 'are able to discern which seedlings are their own kin. [...] The old trees nurture the young ones and provide them food and water just as we do with our own children' (2021). Simard continues:

When Mother Trees—the majestic hubs at the center of forest communication, protection, and sentience—die, they pass their wisdom to their kin, generation after generation, sharing the knowledge of what helps and what harms, who is friend or foe, and how to adapt and survive in an ever-changing landscape (Simard 2021).

Sheila is that mother tree, that individual who sparked a revolution, who built a series of connections and networks and coordinated those growing mycorrhizal networks and in doing so, sustains the other members of the forest. There is an echoing realisation from the words of Donna Riddington pertaining to all the individuals in the room at the screening of the film: 'No one here would have met, if it wasn't for Sheila' (2024). But it is also more than this—all those women gathered in the room to hear Sheila's story re-enacted, collectively witnessed and recollected the potential and power of change held in each individual and for each individual to take a moment to recognise and reflect on their own story, their own journey. As Silvia so eloquently stated:

Sheila's story is so important because it tells a lot about who we are, our strength, our resilience, our craziness, our being rebels, our courage to go against the current, against what the mainstream or the world around us tells us who we should be, and that is why this story matters to me because we can all change things around us, that's what Sheila stands for me. (Petretti 2024).

The making of the film was an extension of this nurturing and complex networking, communicating and protection: an entirely female creative group and crew worked in a manner inspired by Sheila's ethos and approach to getting things done, coupled with Silvia's (a second mother tree) dedication and drive to ensure that Sheila's story is heard. The maternal, collective web theme continues, and the making of the film becomes a family affair with Kat's child taking on the role of Sheila's child. The filming process is one of collective care and support, individuals taking care of each other and holding robust discussions and artistic

debates; the kin at work continuing the traditions of the mother tree.

We first screened the film on International Women's Day, 8 March 2024. That evening, we gathered women who attended the workshops, women who were interviewed for the podcasts and those women involved in Positively UK and sat together with food to watch *Sheila's Story*. The impact of the film, but more accurately, the impact of understanding the impact of Sheila's work is best captured in the words of Charity Nyirenda:

... someone said "Sheila changed the world", I would say Sheila changed everything for me because, to be honest, I didn't know the whole story until today but volunteering for Positively Women changed everything for me, the person who I am today. (Nyirenda 2024).

At this event, we invited the audience to consider the question, 'why is it important to tell Sheila's story?'. In response many began by acknowledging and naming both Sheila but also the women who came before them, some of whom were in that room that evening, to thank them for being there, supporting them, building connection with them, making roots and connections. Here it is important to share some of these statements—the affectual mycorrhizal networks being acknowledged:

If it wasn't for Julie I wouldn't be here on a panel speaking in public - at the launch of *Sheila's Story*, and beyond. Watching Julie and following her journey of being open about her status inspired me to speak about my status openly, in public spaces. (Angelina Namibia speaking about Julie Reynolds (Namibia 2024)).
You were my rock. You were there and the first person I saw. (Helen referring to Sarah Fraser, (2024).

The privilege of being in that room, of witnessing and hearing how these individual stories, these tree roots have been strengthened and have adapted like vines, growing on and off each other, the connections have adapted and they lift each other up, support each other through interconnected roots and growth. Fundamentally, this project has underlined the value and urgent need for spaces to be held in which women can take up room to reclaim their own narratives about their lived health condition. The following quotes are from the feedback card from the women in the room:

To let other positive women become courageous, let them know the power of support from people who are facing the same challenge (Anon 1 2024).

To remember bold rebellious courageous women and the legacy they can create. To inspire young women to continue to trail blaze. It gives an understanding of the unsurmountable issues that had to be overcome to create what we have today. To show how peers and 'experts by experience' can lead and lead well, to make significant changes and fill the gaps that mainstream services neglect. Fucking women are Fucking great! (Anon 2 2024).

CONCLUSION

Taking a close reading of this work, the practice has resulted in a building of an entangled mycorrhizal networks, a community of individuals, whose knowledge shared allows a passage to another type of growth or journey. The legacy of this project lives in the creation of this repository of knowledge, in capturing these stories and honouring these herstories, where the legacy of the work of Positively Women is held and added to. We can acknowledge that embodied feminist performance-making is a means of knowledge production: we have learnt about different

experiences of what it means to live in a gendered, medicalised body—many of the women’s fury and despair at being ‘seen’ as ‘ill bodies’ renders them ‘unseen’ and treated by the GPs by either being dismissed, patronised about how much they know about their condition or given ‘eyes on stalks’—the long ‘ohhhhh you have HIV’ look, of seeing each other as different and beings of multiple possibilities, and finally of capturing and sitting with the complexities of the herstory of the organisation and individuals’ lived experiences. This knowledge allows for multiple understandings and experiences to be equally appreciated and validated. Finally, through the different creative outputs and processes, we have rejected the gendered, medicalised body by illustrating the multiplicity of women’s lives, and lived experiences, their HIV status being one sole aspect of who they are. We are continuing to extend the legacy of DEFEND, DEFEND, DEFEND.

Twitter Katharine E Low @katlow17

Acknowledgements Positively Women and now Positively UK has always had a strong, matrilineal network, it has built an extensive community for individuals living with HIV. The performance-making has extended this connectivity—the playing through creative endeavours allows for individuals to be witnessed in different ways: from the CEO being ‘dragged’ up as a drag king in a recent workshop around power and identity in March 2024, to the kindness and communal love and affection being extended to Kat following the death of her father in January 2024. Connections and entangled networks continue to be made.

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NOTES

- Positively UK’s mission is to ‘unwavering[ly]... empower and support individuals living with HIV, by providing the knowledge, tools, and connections they need to live fulfilling lives and reduce the stigma surrounding HIV’ (2024).
- Fiona has requested we use only her first name. Throughout the article, some interviewees who attended or have run Positively UK-related events will be referred to either by their full name, their first name or as ‘Anon’ following their preferences and requests.
- The other editor was Kate Thomson, one of the early founders of Positively Women.
- The UK AIDS Memorial Quilt is a collection of quilts commemorating the lives lost to HIV/AIDS in the 1980s and 1990s. In July 2023, the UK AIDS Memorial Quilt Conservation Partnership put on an exhibition of all of the quilts in the UK collection. More information about this event can be found here.
- For a detailed discussion of the idea of ‘living well with HIV’ see Low 2024.
- See, for example, in films produced such as *Milk* (2008), *Philadelphia* (1993), *And The Band Played On* (1993) and *Longtime Companion* (1989), television soap operas in the UK (eg, *EastEnders* and *Coronation Street*) and dramas (Channel 4’s *It’s A Sin* (2020)). Theatrical performances in both the UK and the USA have also predominantly focused on the male-identifying, queer or LGBTQIA+ experience, including in the US Larry Kramer’s *A Normal Heart* (1985), Tony Kushner’s *Angels in America* (1992), and Jonathan Larson’s *RENT* (1993), while more recent productions in the UK have included *Outbox Theatre’s Affection* (2016), Patrick Cash’s *The Clinic* (2016), and Camden People’s Theatre’s intergenerational participatory *Kings Cross* (REMIX) (2017).

- This is discussed in depth in Kat’s article ‘The potential of radical kindness as a methodology in applied theatre in arts and health’ (Low 2021).
- Applied theatre is an umbrella term often used to describe a form of theatre-making with, by and for communities and individuals. Often practised in non-traditional theatre settings, it is sometimes referred to as socially engaged theatre. The practice’s intention is to create work addressing social concerns identified by those who participate in the work. For more information, please see *Critical Perspectives on Applied Theatre* (Hughes and Hughes 2016) and *On Access in Applied Theatre and Drama Education* (Conroy, Adelina, and Dirk 2020).
- When Kat was delivering one of her first workshops with Positively UK in 2016, Silvia reminded her of the importance of working with both the ‘shadow and the light’ of women’s experiences of living with HIV; to not ignore the difficult and unsaid experiences.
- For more information about the materials held at the LMA please see Positive History – Positively UK and Mildmay Mission Hospital - City of London and you can search the catalogue here.
- In 2024, we had been co-running a project called ‘Power Bags - Rebel by Default’, holding conversations with women living with HIV about their knowledge and experiences and what they hold close. In a discussion on 16 March 2024, the women noted that people need ‘to LISTEN LOUDER’.
- For example, *A Positive Life* fronted by Sam Smith predominantly focuses on Terry Higgins and the development of the Terrence Higgins Trust. While Marc Thompson’s 2022 *We Were Always Here* offers a broader account of the British experience of living with HIV. Similarly, fronted and developed by CHIVA, a charity which supports children and young adults who live with HIV, offers a whole population view of living with HIV including the excellent Positive Advice Podcast: International Stories from Young People Living with HIV (2023) and *The ArchVive* (2019), which focused on sharing poetry, music and drama created by young people living with HIV.
- Similarly, the 2022 BBC’s *Aids: The Unheard Tapes* series also solely focuses on men’s stories, bringing to life through lip-syncing by actors, the stories of men recorded in the early 1980s through to the 1990s and the ‘Lazarus effect’ of treatment. The recurring message is that women’s experience of living with HIV is not important enough to take the mainstage.
- Leigh was among the first group of women to join Positively Women’s staff team as Service Manager and also set up the first outreach project to support women with HIV in prison.
- This link provides access to the first Positively Present, Positively Past podcast interview with Caroline and Kate.
- More information about the herstory and development of the International Community of Women Living with HIV can be found here.
- Read an account of this herstory written by Jo Manchester and listen to her interview here.
- Listen to Carolyn and Fiona’s interview on the podcast here.
- You can listen to Cinzia and Sophie’s podcast interview here.
- Please listen to Angelina and Rebecca’s interview here.
- Which you can listen to here.
- Here we strongly recommend reading *Our Stories Told By Us: Celebrating the African Contribution to the UK HIV Response* by Angelina Namiba, Charity Nyirenda, Memory Sachikonye, Rebecca Mbewe, Winnie Ssanya Sseruma (Namiba *et al* 2023).
- Please follow this link to listen to Janine’s interview.
- You can listen to Jane’s interview here.
- Listen to Shema and Rageshiri’s interview on the podcast here.
- Please listen to Malika and Chiesa’s interview here.

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