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**Growing Forward Together:
Exploring the Design of Social
Support Interventions alongside
Women Living with HIV
in the UK**

Kiersten Hay

PhD

2021

Growing Forward Together: Exploring the Design of Social Support Interventions alongside Women Living with HIV in the UK

Kiersten Hay

A thesis submitted in partial fulfilment of the
requirements of the University of the
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Design & Social Sciences

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Abstract

The provision of social support services for those living in the UK with Human Immunodeficiency Virus (HIV) is a complex research context for critically exploring Digital Health and Design. Extant work in the HIV sector and in the field of Human Computer Interaction (HCI) has highlighted the need to further understand the contexts in which HIV digital tools and services are created and used. The design and use of digital services and tools for *women* living with HIV is particularly under-researched, despite women making up over half of the global population of people living with HIV.

Women living with HIV are uniquely affected by intersectional inequalities that may limit or negate the effectiveness of digital interventions; these same factors increasing need for HIV social support services. In the UK, this need has exceeded service availability, as austerity measures continue to limit or reduce service provision. HIV social support providers continue to adapt; however, community-based digital innovations are largely uncaptured within academic discourse. I take a Community-Based Participatory Design (CBPD) approach to explore and build upon current HIV social support service provision (and its use of digital technologies) for women living with HIV in the UK, addressing the gap in contextual use knowledge, and pushing towards possible futures.

I have combined qualitative research with design practice across four studies, working alongside UK-based HIV social support service providers to collaboratively define community knowledge and co-create design artefacts. This approach differs from existing HCI studies on HIV that largely focus on the evaluation of researcher-led digital interventions. I argue that, within a design praxis, a researcher-led approach risks perpetuating inequalities and does not ethically engage with the communities it seeks to support. My thesis contributes empirical insights and a novel methodological extension to CBPD for Fourth Wave HCI designer-researchers working alongside marginalised communities.

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Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval was sought and granted by the departmental Ethics Committee at Northumbria University on 2 July 2018, 10 January 2019, and 17 October 2019.

I declare that the Word Count of this Thesis is 89,289 words.

Name: Kiersten Hay

Signature:

Date: 3 September 2021

1 Introduction

1.1 Background and Motivations

The work of communication designers has impacted personal and public conceptualisations of what Human Immunodeficiency Virus (HIV) is, and what it means to live with it, since the 1980s. Public health campaigns, protest posters, advertisements, and more have all worked to shape beliefs about HIV, for better or for worse. Today, communication designers work with people living with HIV, and their healthcare and social support service providers, to craft artefacts that communicate important health and care information, whilst challenging negative beliefs about HIV (or HIV-related stigma). Examples of this include co-designed posters for public health communication (A. Bennett et al., 2006), printed health resources (And Also Too, 2015), and using research through communication design practice to identify structural barriers to health through voiced personal experiences (Wizinsky, 2019). Communication design praxes such as these utilise the rhetorical function of communication design artefacts (Forlizzi & Lebbon, 2002), persuading viewers to adopt new beliefs by referencing existing ones (Tyler, 2006). Critically engaged communication designers choose which beliefs artefacts reference by co-creating a shared language with their intended audience(s) (ibid.); working together, they explore how lived experience may inform design choices that argue for emancipatory (J. Bardzell & Bardzell, 2015) perception change. This rhetorical function embraces socio-materiality, the conceptual approach that material artefacts actively communicate knowledge through their designed form (Frauenberger, 2019). Whilst the importance of socio-materiality has been evidenced within Communication Design methods and artefacts made for HIV health promotion (And Also Too, 2015; A. Bennett et al., 2006) and historical records (Wizinsky, 2019), socio-materiality is less researched *within* the provision of HIV

health and social care services, including Digital Health interventions, for people living with HIV.

The importance of socio-materiality within the design of HIV healthcare and social support interventions is underscored by the ongoing negative impact of HIV-related stigma. Within the UK, HIV-related stigma continues to exist despite medical¹ and social advances (National AIDS Trust & Fast-Track Cities London, 2021). Socially created, shared, and upheld, HIV-related stigma leads to impaired Quality of Life (QoL) for those living with the condition in a number of ways, including socially (e.g. interpersonal relationships) and psychologically (e.g. internalised stigma). The ongoing impact of HIV-related stigma has been compounded by decreased funding and increased service need within the HIV sector since 2008 (Aduaka et al., 2018; Dalton, 2016); funding for the provision of HIV healthcare and social support services dropping from £55 million in 2001/02 to just over £10 million in 2014 (Godfrey, 2015). Experiences of discrimination, violence, and abuse within healthcare settings have continued to be reported by people living with HIV in the UK as a direct result of their HIV status (Auzenbergs et al., 2018; Public Health England, 2020b; Sophia Forum & Terrence Higgins Trust, 2018), and socio-medical research has noted the ongoing reality of HIV stigmatisation within non-HIV-specialist healthcare settings (Baylis et al., 2017; Hedge et al., 2021). These reports foreground the importance of socio-materiality within the provision of HIV healthcare and social support services, as designed interventions meant to facilitate everyday experiences may also support or challenge ongoing stigmatising beliefs about HIV.

¹ Advances in medical treatment mean that HIV can be managed as a long-term health condition (LTC): maintaining adherence to HIV medication results in an undetectable viral load, making it impossible for the virus to pass on to anyone else (also known as Undetectable Equals Untransmittable, or U=U (Rodger et al., 2016)), and also leads to normal life expectancy.

Although funding for HIV healthcare and social support services has decreased in the UK, there has been increasing interest and funding in the potential for digital health and social care² tools and services more widely. In February 2017, Public Health England (PHE) released a corporate report on their intention to pursue Digital Health as a major cornerstone of health and social care (Public Health England, 2017). This was given as crucial to benefit from modern advances in digital technological care provision, as well as modern sensibilities. In January 2019, the NHS Long Term Plan was released, outlining a renewed focus on Digital Health initiatives and addressing health inequalities (NHS, 2021). This was soon followed by the instatement of NHSX in July 2019, a new NHS department responsible for “driving digital transformation and leading policy, implementation and change” (ibid.). The potential for UK investment in digital technologies to address health inequalities in relation to HIV could offer opportunity and financial means to support the design of potentially transformative digital tools and services for people living with the condition. However, given well-documented pervasive HIV-related stigma within the UK (National AIDS Trust & Fast-Track Cities London, 2021), it is crucial that designers of digital healthcare and social support interventions consider how these digital artefacts support or challenge negative HIV beliefs.

² Social care differs from social support, however they share common consideration for how supportive services may complement specialised clinical care to increase QoL. Within the context of HIV-specialised care within the UK, social support services are viewed as an essential part of the HIV care pathway, with the National AIDS Trust noting that “HIV support services reflect perfectly the current ambitions of our health and social care system for person-centred, holistic long-term condition management” (The National AIDS Trust, 2017, p. 5). In this way I view HIV social support services as a part of a broader provision of social care, however this thesis focuses on social support services explicitly.

In the field of Human-Computer Interaction (HCI), focus on how artefacts actively shape knowledge through their socio-materiality is presently dawning within 'Fourth Wave' thinking in this field, or 'Entanglement HCI' discourse (Frauenberger, 2019). Whilst HCI has traditionally configured human-computer interactions grounded in human-centred relations, needs, desires and experiences, the Fourth Wave paradigm shift acknowledges the interdependencies between people and things ('humans and non-humans'), highlighting how designed things play an active role in meaning-making (ibid.). This understanding is influenced by Post-phenomenology and relational ontologies, and opens doors for designers working in stigmatised health contexts to use digital technologies to affect perception change. This approach builds on Design-led Emancipatory HCI discourse (J. Bardzell & Bardzell, 2015), pushing towards possible futures by *creating the things that enact them*.

Digital Health tools and services have previously been found to be acceptable for people living with HIV (Conserve et al., 2016; Cooper et al., 2017; Henny et al., 2018; Nguyen et al., 2019; Pellowski & Kalichman, 2012; Ronen et al., 2020; Taggart et al., 2015), and present a new medium for Communication Design to affect negative beliefs about HIV. However, extant academic research offers limited insights for communication designers seeking to challenge HIV-related stigma through the design of Digital Health tools and services. Most research in the field of HCI on HIV has focused on the outcomes of Digital Health interventions for HIV prevention and medication adherence, rather than user perception or wellbeing (as discussed later on in 2.1.4). As such, these studies provide little to inform the design of digital tools or services that address negative beliefs about HIV.

The potential for digital tools and services to be used within long-term HIV social support services, such as advice or information services, self-management education, and peer support, also remains underexplored (Ronen et al., 2020). HIV social support services include “any service provided to meet HIV-related needs of people living with HIV, other than those provided as part of primary or secondary clinical care,” and are predominantly provided by the HIV voluntary and community sector (The National AIDS Trust, 2017, p.13). I refer to these services as ‘social support services’ to demarcate them from clinical healthcare services and reflect how their rich variance is united through consideration of the social impact of HIV on daily life (ibid.).

Social support services like peer support have been shown to impact negative HIV beliefs and increase QoL for people living with HIV (Positively UK, 2017). This presents a novel design space in which Communication Design methods and artefacts may be useful in the design of digital tool and services; utilising the rhetorical focus of Communication Design to help support the delivery of HIV social support services that seek to change negative HIV beliefs. This approach builds upon the legacy of communication designers working alongside people living with HIV to co-create artefacts that challenge stigmatising beliefs about HIV and what it means to live with it (And Also Too, 2015; A. Bennett et al., 2006; Wizinsky, 2019). Within this thesis I apply this socio-material lens to designing digital tools and services intended to be used by *women* living with HIV in the UK specifically.

Women living with HIV are underrepresented within academic research despite making up over half of the 38 million people living with HIV globally (UNAIDS, 2020). In the UK, women account for a third of all people living with HIV (Public Health England, 2020a).

Intersectional inequalities in relation to gender, race, and socioeconomic status have led to the further marginalisation of this group, compounded by a lack of representation within HIV research, policy, services, and popular culture (Durvasula, 2018; Sophia Forum & Terrence Higgins Trust, 2018). Women are uniquely affected by sociomedical aspects of HIV related to gender, such as gender-based violence (Orza, Bewley, Chung, et al., 2015), however their experiences have been rendered largely invisible within the response and narrative of HIV within the UK (Sophia Forum & Terrence Higgins Trust, 2018). Women living with HIV in the UK experience higher levels of poverty than men and report higher levels of need of social support services (A. Brown et al., 2019). These factors, in conjunction with the negative impact of austerity measures on HIV social support service provision (Dalton, 2016), fuel both the importance and precarity of HIV support services for women living with HIV in the UK (Sophia Forum & Terrence Higgins Trust, 2018). Furthermore, although Digital Health interventions have been shown to be acceptable for *some* women living with HIV (Tufts et al., 2015), research within the HCI field has also highlighted that social inequalities in relation to gender may have detrimental effects on the success of digital interventions within this population (Natarajan & Parikh, 2013).

Designing digital interventions for HIV social support services is further complicated by the limited academic research on how digital technologies are used by HIV social support service providers (Ronen et al., 2020; Taggart et al., 2015). To date, the majority of Digital Health research in HIV and HIV HCI has instead focused on the evaluation of bespoke, researcher-led interventions that primarily target medication adherence or HIV prevention. Evaluation of HIV social support interventions for women that are designed and delivered by service providers have been noted to be largely absent

from academic review, despite the likelihood of them being more locally appropriate and financially sustainable (Beres et al., 2017). Additionally, researcher-led digital HIV interventions often focus on measuring objective criteria, which arguably focus on what needs to be improved or 'solved' through design. Community-Based Participatory Design (CBPD) discourse within the HCI field has shed light on how such 'damage' or 'needs-based' research approaches can perpetuate stereotypical or stigmatising narratives about marginalised populations, rather than building towards effective change (Harrington, 2020; Wong-Villacres, Gautam, et al., 2020). In conducting my doctoral research mindful of the ongoing negative effects of HIV stigmatisation (Hedge et al., 2021; National AIDS Trust & Fast-Track Cities London, 2021; Public Health England, 2020b), I purposefully use strength and asset-based approaches to conduct design research with women living with HIV and their service providers to support sustainable and effective digital innovation (Namiba et al., 2016).

My doctoral work began with a simple motivation: I had the opportunity to undertake three years of independent research and I wanted to make it as useful to women living with HIV in the UK as possible, within the limits of my abilities. As a critically engaged designer-researcher I was aware of the privilege of my position, and the responsibility of meaningfully and respectfully representing the experiences of others within a marginalised topic space. As a cisgender White woman not living with HIV who is also not a UK citizen³, I was also aware of my difference on several fronts from the women who I would work with, and how this would likely have shaped my perceptions and beliefs to be different. These considerations were at the heart of the challenges in designing,

³ I am a Canadian citizen.

researching, and otherwise representing an experience that I knew nothing about, holding ripe potential for misrepresentation, harm, and extractive practices. This positioning informs my use of Critical Phenomenology within my design-research praxis, seeking to understand the everyday experiences of others with acknowledgement of how *ways of seeing* and *making the world* are coloured by historical and social structures of power (Guenther, 2020). As a *designer*-researcher I had the expertise to make more than research, and I wished to find a way to engage in an ethical design praxis whilst working in a complex interdisciplinary space.

This doctoral programme of work addresses several gaps in knowledge and pushes towards possible futures in coalition with women living with HIV in the UK. Specifically, I seek to address gaps in knowledge on (1) the use of digital technologies by women living with HIV in the UK; (2) how digital tools and services are designed and used within HIV social support services for women living with HIV in the UK; and (3) what approaches can inform design praxes involving Digital Health tools and services within stigmatised health contexts. In the studies reported herein, I have worked alongside women living with HIV in the UK and their social support service providers as an 'expert' (Manzini, 2015) designer-researcher, articulating a novel methodological extension to CBPD in order to illuminate how digital technologies are designed, used, and understood within service provision. This doctoral work represents the first set of studies conducted into the use of digital technologies by service providers for social support provision for women living with HIV in the UK. Insights are grounded in empirical studies that focused on understanding the lived experiences of communities of individual women, and co-creating meaningful research and designed artefacts to push towards possible futures with them. In positioning my work within Critical Phenomenology (Guenther, 2020)

I entwine my research insights into the lived experiences of women living with HIV with critical reflexivity on my role as a designer-researcher, a position of power that calls for ethical responsibility within my work.

I take a Fourth Wave (Frauenberger, 2019) approach to HCI Design research to consider how I, as a designer-researcher, might meaningfully and ethically co-design digital interventions that recognise the complex socio-material entanglements inherent to social support service provision within stigmatised health contexts. This includes reflecting on my own positioning as a White cisgender woman not currently living with HIV or UK citizenship, and the responsibility and influence that my work entails in this space. Through this approach, I go beyond understanding how HIV social support services use digital technologies for service provision, additionally considering how designed artefacts may support the meaningful and emancipatory work of social support by actively affecting perception change within a stigmatised health context.

Furthermore, the latter phases of my doctoral work have taken place in the wake of the COVID-19 pandemic, during which digital HIV service provision has become the norm in the UK for the research partners and participants I was engaged with. HIV social support service providers have had to rapidly adopt and adapt to digitally mediated service provision, utilising digital tools and services that were appropriate to their clientele and feasible to implement with available resources; this experience will inform how HIV social support services are facilitated in future. My work on digital HIV social support service provision has therefore gained particular salience during this period. I aim for the findings from my PhD studies to inform responsible digital and methodological innovation; positioning Community-Based Co-Design Praxis as a means for HCI

designer-researchers to help grow towards the emancipatory co-creation of worlds that we wish to live in.

1.2 Research Aims, Questions, and Objectives

The overall aim of this doctoral programme of work was to explore how 'expert' design praxes (Manzini, 2015) may be used within CBPD research within stigmatised health contexts. My studies were guided by three Research Questions (RQs).

(RQ1) How does lived experience impact on the conceptualisation and use of digital technologies by women living with HIV in the UK? I aimed to understand the contextual use of digital technologies by women living with HIV within daily life in order to inform the design of appropriate digital social support interventions. My specific objective was to:

- Gain empirical insights into what factors impact digital technology use by women living with HIV in the UK, based on their reported experiences.

(RQ2) How are digital tools and services designed and used within HIV social support services for women living with HIV in the UK? I aimed to understand how digital tools and services are created and used by HIV social support service providers in the UK, in order to support responsible research and innovation involving the design of digital interventions for women living with HIV. My specific objectives were to:

- Provide research insights into how digital tools and services are *developed* in the field, in order to pragmatically align design research activities.
- Provide empirical insights into how digital tools and services are *used* in the field by women living with HIV, to inform design innovation.

(RQ3) What approaches can inform design praxes involving Digital Health tools and services within stigmatised health contexts? I aimed to understand how ‘expert’ designers (Manzini, 2015) working with the HCI field who do not have personal experience living with stigmatised health conditions may approach designing digital tools and services for service provision to those populations of users. My specific objectives were to:

- Deliver methodological insights into best practices for engaging in design praxis within complex and stigmatised health contexts
- Provide worked example(s) of appropriate design praxes for working with women living with HIV to inform related research fields.

1.3 Overview of Approach

This doctoral work is exploratory, as it represents the first research using a Design-led approach to illuminate the contextual use of digital technologies by women living with HIV for social support services in the UK. In order to support methodological development alongside Fourth Wave HCI (Frauenberger, 2019) discourse in Design, I establish the methodological foundations of a novel extension to a CBPD, Community-Based Co-Design Praxis, to help guide responsible ‘expert’ design praxes (Manzini, 2015) within complex and stigmatised health contexts. This approach builds upon the best practices of: Community-Based Participatory Research (CBPR) approaches within the HIV sector (Bird et al., 2017), as advocated for women living with HIV (Namiba et al., 2016); Community-Based Participatory Design (CBPD) approaches used within HCI Design discourse involving marginalised communities (Harrington, 2020; Wong-Villacres, Gautam, et al., 2020); and combining these approaches with critically-informed empathetic (C.

L. Bennett & Rosner, 2019) 'expert' design praxes (Heiss, 2019). My approach is further informed by Critical Phenomenology (Guenther, 2020); I challenge Third Wave Interaction Design approaches (Zimmerman et al., 2007) by considering the socio-materiality and practicalities of actual use as integral components of a responsible design praxis. *Configuring Community-Based Co-Design Praxis*, I have conducted my research and design praxes alongside women living with HIV in the UK and their service providers.

The doctoral studies presented herein represent an unfolding understanding of the research subject that has been co-created with my collaborators and participants. In taking a community-based approach, all design and research works have been discussed, planned, and reviewed with their respective collaborators. While community involvement ranges between individual works, from light-touch planning and review to active collaboration along every stage of research, these collaborations have been guided by their respective arrangements. These research works have also been reviewed by their related stakeholders prior to inclusion within this doctoral work. Insights gathered from across all four works were then independently linked and expanded upon within the Discussion Chapter (8.0) to capture unfolding understanding in response to my three research questions.

In conducting my doctoral project alongside my collaborators, I shed light on how community-based Communication Design methods and artefacts may contribute novel insight into the socio-materiality of digital artefacts for Fourth Wave (Frauenberger, 2019) HCI Design discourses. Insights gained through my programme of work underscore the critical importance of understanding the socio-materiality of Digital Health tools and services within stigmatised health contexts, and highlight the utility and ethics of using

community-based approaches to co-create this understanding with others. Additionally, worked examples of how Design-led research approaches produce unique socio-material insight offers transferrable guidance in how to design appropriate digital tools and services within stigmatised health contexts for HCI and related Digital Health research fields.

1.4 Thesis Structure

My account of the doctoral work informing this thesis begins in Chapter 2 with a Contextual Review (Gray & Malins, 2017) of previous research and design work, grouped into three major sections: *HIV, Doing Design Research & Praxis*, and *Designing in Stigmatised Contexts*. Chapter 3 then describes my novel methodological extension of CBPD, Community-Based Co-Design Praxis, in relation to current Co-Design and empathetic design praxes within HCI discourse. The subsequent four chapters then report on my four respective doctoral works chronologically. Chapter 4 describes my first focus group discussion with women attending a peer support group at Blue Sky Trust (BST)⁴, a local charitable organisation providing HIV social support services in Newcastle-upon-Tyne. Chapter 5 provides a reflective account of my work with a leading national HIV organisation, National AIDS Trust (NAT)⁵, during an internship post that I held during my PhD working in a team creating a digital informational support tool. Chapter 6 focuses on my second empirical study conducted with 4MNetwork⁶, a women's HIV peer support network, evaluating their use of WhatsApp for service delivery. In Chapter 7 I then describe my process of co-creating a

⁴ For more information about Blue Sky Trust, see (Blue Sky Trust, 2021)

⁵ For more information about the National AIDS Trust, see (The National AIDS Trust, 2021)

⁶ For more information about 4MNetwork, see (4MNetwork, 2021)

zine publication, 'The Rose of Love', with members of the women's peer support group at BST, to be used in service delivery for women newly referred to the organisation. I synthesise insights from these four chapters together in Chapter 8, addressing my research questions and reflecting on my design praxis and the limitations of the studies. In Chapter 9 I present my concluding statements and summarise key contributions.

In *Chapter 2: Contextual Review*, I synthesise foundational and current literature with examples of Communication Design artefacts to inform my rationale and background for my doctoral work.

I first introduce the current landscape of HIV in terms of epidemiology and demographic profile of HIV in women, establishing a picture of women living with HIV in the UK and underlining the importance and precarity of HIV social support services for this population (Sophia Forum & Terrence Higgins Trust, 2018). I draw attention to the unique benefits of HIV peer support for women in the UK and highlight the lack of academic research on digital interventions used by HIV social support service providers (Beres et al., 2017). I then situate current HCI discourse involving HIV to illuminate the shared gaps in knowledge between broader HIV eHealth and HCI Digital Health discourses on digital social support interventions for women living with HIV. I identify the need to develop contextual understanding on the use of digital technologies by women living with HIV and their service providers in order to support appropriate and sustainable digital innovation within this space.

In response to this context for design research I then align my research approach within Community-Based Participatory Design (CBPD) discourse (DiSalvo et al., 2012). I provide a foundational understanding of the CBPD approach, drawing attention to its use

within the HCI field. I then identify CBPD's concept of 'infrastructuring' (Star & Ruhleder, 1996) as a conceptual basis for how designer-researchers may seek to understand socio-materiality while co-creating digital artefacts fit for use within marginalised contexts. I align CBPD sensibilities (Harrington, 2020; Wong-Villacres, Gautam, et al., 2020) with current movement towards a Fourth Wave (Frauenberger, 2019) HCI research paradigm; outlining how CBPD approaches resonate with Fourth Wave considerations of socio-materiality in relation to the accountability, responsibility, and ethics of design research practices. I then identify a gap in knowledge in how these ethical considerations relate to the co-design of research artefacts, underlining the need to understand how designed artefacts may communicate negative beliefs within stigmatised health contexts.

Informed by this positioning, I go on to provide my rationale for considering socio-materiality within a CBPD approach to Design research. I first introduce the concept of stigma (Goffman, 1990) and its ongoing impact on the daily lives of women living with HIV (Hedge et al., 2021; National AIDS Trust & Fast-Track Cities London, 2021). I then present contemporary approaches to researching and representing experiences of stigmatisation from Critical Disability Studies discourse (S. E. Cahill & Eggleston, 1994; Lofland, 2007), identifying their compatibility with CBPD approaches and Fourth Wave HCI (Frauenberger, 2019) sensibilities. I then situate this approach to research in relation to extant Design discourses and praxes (DePoy & Gilson, 2014; Pullin, 2009), including Design-led Emancipatory HCI (J. Bardzell & Bardzell, 2015), Communication Design (And Also Too, 2015; A. Bennett et al., 2006; Wizinsky, 2019), and Adversarial Design (DiSalvo, 2015), demarcating their similarities and identifying a shared gap in knowledge. Through these examples I outline the need for a craft perspective on how the co-

creation of CBPD artefacts may serve pragmatic purpose while challenging stigmatising beliefs through their normative socio-materiality.

In *Chapter 3: Methodology*, I provide my novel methodological extension to CBPD methodology for using community-based co-design approaches within ‘expert’ (Manzini, 2015) design praxes. I first outline the specific gap in Design and CBPD discourses around how co-creating shared understanding may inform designed artefacts, reflecting on the importance on this to my own doctoral design research and praxis. I then introduce my novel methodological extension for CBPD, Community-Based Co-Design Praxis, and describe its four pillars (Coalition, Conversation, Co-creation, and Critical Ethics) in relation to their (1) respective theoretical foundations within Critical Phenomenology (Critchley, 2014; Derrida, 1981; Levinas, 1969; Stein, 1989) and (2) implications for design praxis. I then justify this extension to CBPD methodology as a means for designer-researchers to consider socio-materiality within Fourth Wave HCI (Frauenberger, 2019) discourse and explicate its difference from Experience-Based Co-Design. I go on to describe how this position informed the research and design methods used within my programme of doctoral work, reported on in the subsequent chapters.

In *Chapter 4: Exploring the Form of (Digital) Peer Support Interventions in Context: How Women Living with HIV Conceptualise and Use Peer Support Services*, I describe my first doctoral study, a focus group discussion with women attending a HIV peer support group at the Blue Sky Trust (BST) charity in Newcastle-upon-Tyne. I present insights into what peer support means for women living with HIV, and how digital technologies support or threaten these valued aspects of service provision. This study establishes my foundational

understanding of how HIV social support service providers use digital technologies within peer support service provision, and how these services impact the beliefs of service users.

In Chapter 5: Reflections on Observing the Collaborative Development of a Digital Tool for Informational HIV Social Support, I describe and analyse my internship experience with the National AIDS Trust (NAT) using a Reflective Design (Sengers et al., 2005) approach. I present three reflective vignettes of key design activities used within the collaborative development of 'Looped in,' a digital HIV informational support tool. I then use a Design Praxis Matrix (Chung, 2019) as an analytic tool to illuminate insight into how digital tools are developed by HIV service providers, identifying areas in which 'expert' design praxes may be meaningfully positioned as translational agents to support responsible digital innovation.

In Chapter 6: Supporting the Supporters: Digital HIV Peer Support for and by Women Living with HIV in the UK, I describe a co-research interview study (conducted with a peer researcher) on the use of WhatsApp by members of 4MNetwork (4MNet), a national peer-led mentorship programme run by women living with HIV for women living with HIV (Hay et al., 2020). I present insights on how 4MNet mentors and management team members use WhatsApp in relation to 4MNet programme values, illuminating factors impacting the use of digital technologies by women living with HIV and how 4MNet has designed its use of WhatsApp in response.

In Chapter 7: "It's all about the journey": Co-Creating a Zine for New Referrals to an HIV Peer Support Service alongside Women living with HIV, I describe a co-design study in which I co-created a zine publication with members of the women's peer support group at BST, intended for new referrals to the organisation. I present how this

novel zine-making method illuminated insight into how key experiences within the HIV journey were visually communicated and narratively linked by women living with HIV within a co-designed artefact. I then reflect on how this study's co-creative process supported the creation of a shared language with my collaborators that both expressed and challenged beliefs, underscoring the importance of Making activities within design research.

In *Chapter 8: Discussion*, I bring together insights from my doctoral works and respond to my three research questions. In meeting their respective objectives, I contribute new knowledge to advance interdisciplinary discourses involving the design of digital HIV interventions. I then offer a summary of these contributions and reflect on the limitations of this doctoral work and recommendations for future work.

In *Chapter 9: Conclusion*, I summarise my contributions to interdisciplinary discourses involved in the design of digital HIV interventions and offer recommendations for future applications of Community-Based Co-Design Praxis. I then close with a personal reflection on my experience in conducting this doctoral work.

1.5 Contributions

The key contributions of my doctoral work are presented in the Discussion Chapter of this thesis account (8.0), but a brief summary follows.

- I contribute empirical insight into what factors impact digital technology use by women living with HIV in the UK, based on their reported experiences, for interdisciplinary discourses involving the design of digital HIV interventions (RQ1)

- I contribute research insight into how digital tools and services are *developed* in the field in order to pragmatically align design research activities (RQ2)

- I contribute empirical insight into how digital HIV social support tools and services are *used* by women living with HIV in the UK, shedding light on how HIV social support service providers have designed their use of digital technologies to mediate service provision in ways appropriate to their clientele (RQ2)

- I contribute methodological insight on best practices for engaging in design praxes within complex and stigmatised health contexts, demonstrating the importance of socio-materiality for effective and appropriate service provision (RQ3)

- I contribute worked example(s) of appropriate design praxes for working with women living with HIV to inform related research fields, responding to the interdisciplinary gap in research involving women living with HIV (RQ3)

The contributions made through this account of work are situated within interdisciplinary academic discourses. Community-based approaches to Communication Design praxis guide my approach to entering this research space, however it is of ethical importance that these insights translate to broader HIV and HCI discourses involving digital HIV interventions in order to support responsible digital innovation. I introduce these academic fields and position my work among them in the next chapter of this thesis.

2 Contextual Review

I now turn to describe the multi-disciplinary research landscape that my doctoral work is situated in and has aimed to contribute to, highlighting challenges and areas that remain under-explored, and the socio-political context and relations that I have responded to in my studies that follow.

2.1 HIV

2.1.1 Introduction

I begin this chapter by looking at current discourses on HIV, as this is the arena which my work draws from and operates within.

As I apply my design praxis specifically within the context of women living with HIV in the UK, I first establish a picture of this group using existing data, revealing an unmet need in relation to social support (2.1.2). I go on to present existing work within the UK on HIV social support in order to inform my design praxis within this space (2.1.3). From this context I draw specific attention to HIV peer support⁷, including current practices and programmes, to inform my approach to designing for peer support interventions (2.1.3.1). I then investigate the current use of digital tools and services for HIV peer support, outlining specific gaps in knowledge within HIV discourse (2.1.3.2). Finally, I present an overview of current HCI discourse involving HIV in order to illuminate the shared gaps in knowledge between broader HIV eHealth and HCI Digital Health discourses involving people living with HIV (2.1.4).

⁷ Where social support is provided by individuals with shared lived experience(s) to those being supported.

2.1.2 Women living with HIV in the UK

I begin by providing a brief demographic overview of women living with HIV, with statistics taken from the National HIV surveillance data tables produced by Public Health England (PHE) (Public Health England, 2020a).

Of the 98,552 people seen for HIV care within the UK in 2019, nearly a third were women. Most women living with HIV are aged 35 or above, with the majority of this group aged between 35-49 years old (approx. 50%). Just over 60% of women living with HIV are of Black African ethnicity, with approximately 20% of women identifying as White⁸. Most women living with HIV reside in England (93%), with smaller populations in Scotland (4%), Wales (2%), and Northern Ireland (1%). Women are diagnosed late⁹ more often than men (48% vs. 41% in 2018, 44% vs. 41% in 2019), with exposure predominantly attributed to heterosexual contact (approx. 91%). I have provided figures on the age, ethnicity, and region of residence data for women living with HIV below (Fig. 1) to illustrate the diversity of this population.

⁸ 'White' is provided as an ethnic category within the National HIV Surveillance Tables with no further subdivision of ethnic categories (e.g., White British).

⁹ Late diagnosis of HIV means that HIV has only been clinically diagnosed after the virus has already begun to damage the immune system, and is noted when one's CD4 count (a measurement of health of the immune system) falls below 350 at diagnosis or within the first three months of diagnosis (Terrence Higgins Trust, 2018).

Women Living with HIV in the UK

National HIV surveillance data tables 2020

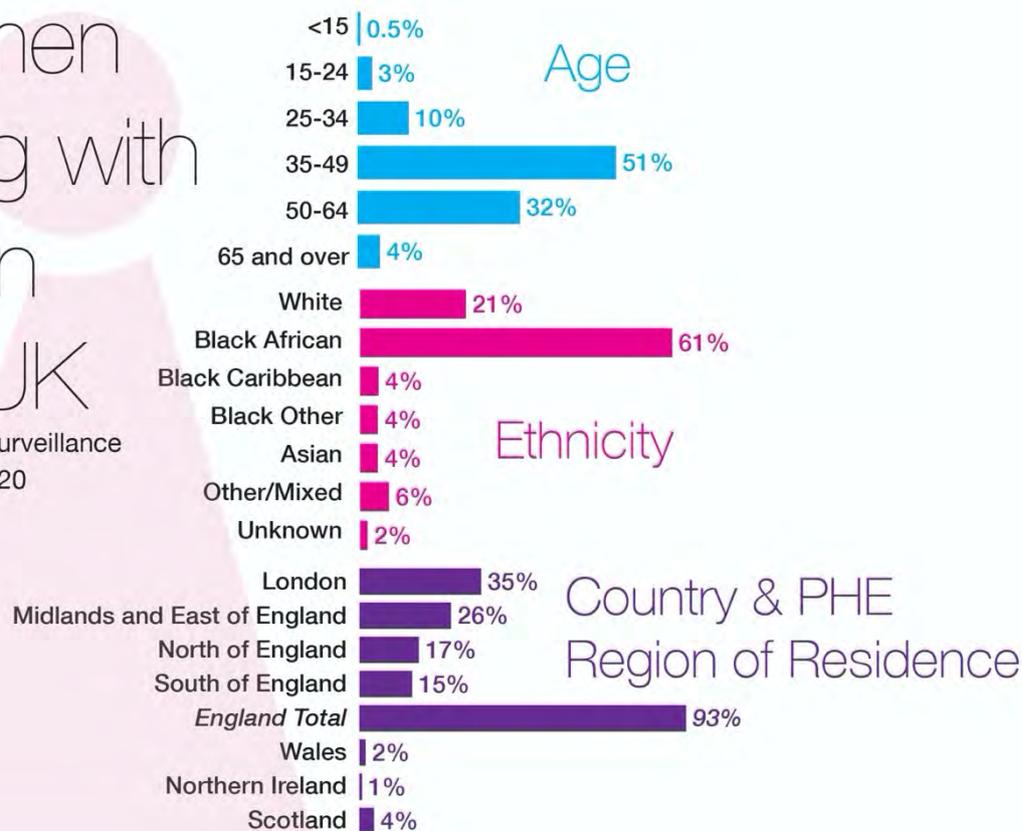


Figure 1: Age, ethnicity, and region of residence data on women living with HIV in the UK. All data taken from (Public Health England, 2020a). Image by Author.

Two key national studies provide further insight into the experiences of care provision among women living with HIV in the UK: (1) 'Positive Voices', a national survey on the experiences of people living with HIV in the UK conducted by PHE¹⁰ in 2017 (Public Health England, 2020b); and (2) 'Invisible no Longer', a mixed methods study focusing specifically on the experiences of women living with HIV conducted by Sophia Trust and Terrence Higgins Trust¹¹ (two

¹⁰ Positive Voices is a national survey study which uses quantitative questionnaires, recruiting participants through local HIV clinics. The 2017 study recruited a representative sample of 4,422 people living with HIV, approximately 1375 (31%) of whom identified as female.

¹¹ The Invisible no Longer report is informed by data collected from 310 online mixed method surveys, participatory workshops involving 32 women, and key stakeholder interviews (Sophia Forum & Terrence Higgins Trust, 2018).

major HIV charities) and published in 2018 (Sophia Forum & Terrence Higgins Trust, 2018).

Within Positive Voices, 97% of women felt supported to self-manage their HIV with the assistance provided by HIV clinical services (Public Health England, 2020b, p. 39). However, while clinical services were reported as being 'very acceptable', the availability of social support services provided by charities and voluntary organisations presented an area of unmet need. Women living with HIV were more likely than men to report having used HIV social support services (44% vs 35%), with 87% of women reporting these services being important for their health and wellbeing (Public Health England, 2020b, p. 45). Despite this, one in three women noted these services had become more difficult to access in the past two years (*ibid.*).

This high need for social support services may be partly related to the economic disparities between men and women living with HIV in the UK. Over two thirds of women in Positive Voices reported that they did not always have enough money to meet their basic needs (Public Health England, 2020b, p. 38). Median annual household income was between £10,000 and £19,999, with 27% of women reporting annual household incomes below this bracket (Public Health England, 2020b, p. 37). In comparison, only 35% of men living with HIV reported an annual household income of £19,999 or under (*ibid.*). Additionally, 15% of women reported being unemployed and 8% reported being on long-term sick or disabled support for at least three months (Public Health England, 2020b, p. 36). By comparison, 6% of gay or bisexual men reported being unemployed, and the overall unemployment rate for women in the UK at the time of data collection was 4.3% (*ibid.*).

Findings presented in the 2018 Invisible no Longer report echo Positive Voices, as well as providing additional insight into the experiences and unmet needs of women living with HIV in the UK:

“Women living with HIV have specific support needs related to HIV as well as needs related to wider health and social issues. Women reported that not everything ‘was about HIV’ and yet HIV can make it harder to access support for other issues”

(Sophia Forum & Terrence Higgins Trust, 2018, p. 9).

Unmet need in relation to HIV support services due to intersecting issues (such as violence, mental health, and immigration) was voiced, and authors emphasised how multiple identity factors and experiences intersected to shape the unique challenges, discrimination, and invisibility encountered by women living with HIV (Sophia Forum & Terrence Higgins Trust, 2018, p. 14).

As the first national study on the experiences of women living with or vulnerable to acquiring HIV in the UK, Invisible no Longer highlights the diversity and complexity of experiences of women living with HIV. Considered together, Positive Voices and Invisible No Longer reports illustrate both the importance and lack of appropriate social support services for women living with HIV. I will now provide a brief overview of HIV support services for women living with HIV in the UK in order to further contextualise my design research praxis.

2.1.3 HIV Social Support in the UK

Social support can be informational (e.g. advice), instrumental (e.g. providing transport), and/or emotional (e.g. providing empathy) (Cohen et al., 2000; Huh et al., 2014). In the UK, HIV social support services are provided by charities and voluntary organisations, with services administered nationally (such as Positively UK), locally (such as Blue Sky Trust in Newcastle-upon-Tyne), or in combination

(such as by Terrence Higgins Trust, a national charity with regional offices).

The charity and voluntary organisations providing HIV social support services in the UK have been severely affected by austerity measures put into action by the government in response to the 2008 global financial crisis and subsequent recession (Aduaka et al., 2018; Dalton, 2016). These financial changes were also followed by a funding shift introduced by the 2012 Health and Social Care Act, in which HIV prevention services were made the responsibility of local authorities rather than NHS Primary Care Services. This change complicated the delivery of HIV social support services, and has led to the continuing risk of closure for non-clinical services (including social support services) due to the precarity of local commissioning decisions and funding, as charities often rely on both funding streams (Baylis et al., 2017, p. 4). Changes to service provision introduced by the 2012 Health and Social Care Act were soon followed by cuts to funding for these services, decreasing from £55 million in 2001-2002 to around £10 million in 2014 (Dalton, 2016). While funding has decreased alongside other revenue streams for charities, many HIV social support organisations report increases in demand (ibid.). This mismatch is reflected within the reports of multiple areas of high unmet social support service need for women living with HIV within the Positive Voices report (Public Health England, 2020b), as well as reports of increased need for social welfare support services (such as food and housing) from HIV social support organisations (Aduaka et al., 2018).

HIV social support service providers have strained to adapt and adopt services to meet the needs of their clientele with increasingly limited resources. Whilst funding is limited and needs are great, the largest categories of unmet need for women living with HIV are either

exclusively or in part addressed by HIV charity or volunteer organisations (see Fig. 2 below) (Public Health England, 2020b). While 59% of women within the Positive Voices study reported needing at least one social and welfare service in 2016-2017, high rates of unmet need suggest there are not enough services or service providers available to meet demand.



Figure 2: Unmet needs voiced by women living with HIV related to services provided by HIV charity or volunteer organisations. Data and categories taken from the 2017 Positive Voices report (Public Health England, 2020b). Image by Author.

For women living with HIV, the fragmentation of service provision is further complicated by intersecting identity factors and experiences, such as immigration status and experiences of homelessness, and the subsequent effects on access and appropriateness of available services, such as mental health support (Sophia Forum & Terrence Higgins Trust, 2018, p. 51). While there are limited data available with which to inform the design of services to address the needs of women living with HIV, Positive Voices and Invisible no Longer together emphasise the importance of capturing the plurality of needs within this diverse population. HIV social support providers

may be best positioned to address this plurality of needs given they provide a variety of supportive services¹². However, they face decreased and unstable funding conditions in which to do so.

The precarious reality of HIV social support provision and the diverse (unmet) needs of women living with HIV in the UK raises pragmatic considerations for a design inquiry into the potential for digital tools and services in this space. In order for any work to be sustainable, interventions must be informed by what is both feasible and acceptable. While HIV service providers are experts in producing and maintaining services that meet these requirements, there has been limited research into their development and use of digitally mediated tools and services.

Within this context, I have focussed my doctoral studies on the design and use of digital tools and services within HIV social support services. Given the limited resources available for service provision within this area, consideration was given to design outputs which could both (1) be utilised without necessarily relying on sustainable investment (both financial and organisational) for design interventions to be feasible in practice; and (2) consider the plurality of needs voiced by women living with HIV in the UK. As discussed in the following subsection (2.1.3.1), these factors were chosen not only to reflect the reality of service provision in this area, but also to build on the work already done (and continuing to be done) at both community and organisational levels in response to these conditions.

¹² HIV social support services may include informational, instrumental, and/or emotional support, with these types of support often blending within service provision (e.g., providing lunch while listening to someone's worries being both instrumental and emotional support).

2.1.3.1 Peer Support

Peer support is defined as support provided by individuals with shared lived experience(s) to those being supported. Peer support methods, such as group meetings and support networks, are an acceptable and successful means of holistically addressing the needs of women living with HIV (Positively UK, 2015). As discussed in the previous subsection (2.1.2), there are limited available data on the diverse needs of women living with HIV, despite evidence of the compounding influence of intersecting identity factors and experiences on service accessibility and acceptability. As peer support provides a range of social support services while also facilitating the sharing of experiences (and creation of new ones) among participants, it represents an optimal space for researching the plurality of needs of this population whilst also being well-positioned to innovate in response to identified issues.

As this research has focused specifically on peer support amongst women living with HIV in the UK, a peer within this context is defined as a person who identifies as a woman and who has received an HIV diagnosis. While peer support unsegregated by gender is available and common for people living with HIV in the UK, I chose to specifically focus on the experiences of women. This was in order to produce empirical insights which address the underrepresentation of women within academic HIV research, as well as to produce insights which may better inform the design of appropriate services for this population.

Peer support for people living with HIV can be provided and received through both formal services (such as those offered by HIV support organisations - sometimes within HIV clinics - in either group or one-on-one delivery formats) and through one's social relationships (such as friends, family members, partners, or spouses also living with HIV)

(Peterson et al., 2012). For the purposes of this thesis, I focus on peer support services offered by HIV social support organisations; however, the ability of peer support to be accessed by people living with HIV in both formal and personal contexts is important to note (ibid.)¹³. By remaining aware of the holistic existence of peer support within daily life while focusing specifically on peer support interventions, I aimed to approach the phenomena of peer support broadly, whilst designing explicitly for HIV social support service delivery.

Within the UK, HIV-related peer support is championed and provided by charity and voluntary organisations, such as Positively UK (Positively UK, 2017). These services aim to support clinical care through involvement at local HIV clinics, linking those living with HIV to other social services, such as housing or employment support. Peer support is also defined as a quality of care indicator by the British HIV Association (BHIVA)¹⁴ (British HIV Association, 2018), including for management of HIV during pregnancy (British HIV Association, 2019). However, peer support services are rarely offered within HIV clinics, and are increasingly rare in the face of the austerity measures previously described (2.1.3), which has resulted in many HIV non-profit organisations closing or reducing services (National AIDS Trust, 2016).

¹³ Building on the work of Cindy-Lee Dennis (Dennis, 2003), authors Jennifer L Peterson et al (Peterson et al., 2012) proposed that peer support was not limited to created social support services alone for people living with HIV in the USA, and as such should be considered broadly in context to several factors: the nature of the relationship (embedded vs. created); level of formality; social and physical distance between participants; and the number of participants involved (e.g. one-on-one or group) (ibid. p. 9-10).

¹⁴ BHIVA is the UK's national professional body representing health care professionals working within the context of HIV.

BHIVA has recognised the importance of peer support within their 'Standards of Care for People Living with HIV', stating that "peer support is a key contributor to optimising self-management as it not only draws on community resources and expertise but allows people to contribute to communities" (British HIV Association, 2018, p. 17). Focus on self-management of HIV can be attributed to both changes in funding to HIV services, as well as the relatively new conceptualisation of HIV. The 2018 BHIVA Standards recognise that the long-term nature of HIV means that diverse and changing resources will be required throughout a service user's lifetime to effectively support self-management of HIV, and that the ability to engage in self-management can be significantly impacted by one's ability to access "material and social resources, including for basic needs" (ibid.). This is important to note given the socioeconomic marginalisation and poor access to services experienced by some women living with HIV (2.1.2), which may constrain their capacity to self-manage HIV.

BHIVA also notes the importance of peer support as a key intervention in addressing 'social inclusion and well-being' for successful self-management specifically (British HIV Association, 2018, p. 18). As an LTC, the benefits of HIV peer support are similar to those in other LTCs. Peer support has been broadly effective as an intervention led by, with, and for those living with LTCs, such as mental health diagnoses (Repper & Carter, 2011) and Type-2 Diabetes (Johansson et al., 2017; Wingate et al., 2017); it has been shown to lower overall costs of medical provision in these areas as well as in HIV (British HIV Association, 2018; Johansson et al., 2017; Positively UK, 2017; Wingate et al., 2017).

In specific consideration of HIV, there are several additional benefits to peer support. It has been shown to improve both the experience(s)

of individual service users living with HIV, and their journeys within medical care (Cabral et al., 2018; Positively UK, 2017). In Jane M. Simoni *et al's* (2011) review of 117 published studies from international sources, peer support was shown to be broadly beneficial in improving knowledge and attitudes towards HIV among service users (Simoni et al., 2011). Peer support has also been shown to help individuals cope with internalised, stigmatising beliefs about HIV (discussed further in the next section), while reducing social isolation and building resilience (The National AIDS Trust, 2016b). Beyond medical outcomes alone, the value of peer support lies in its holistic support approach, with studies highlighting the importance of this focus specifically in reference to under-served populations.

In their review of publications on the effectiveness of peer support for hardly reached populations with diverse health problems (including HIV), authors Rebeccah Sokol and Edwin Fisher (2016) found that peer support “is a broad and robust approach to reaching and benefiting those too often hardly reached,” and that “the breadth of circumstances in which [peer support] is effective suggests that flexibility is a contributor to its success” (Sokol & Fisher, 2016, p. 1). Not only is peer support effective, but the authors also conclude *that peer support may be more effective among hardly reached groups than other demographics* (Sokol & Fisher, 2016, p. 6). Given the marginalisation of women living with HIV, peer support is potentially a uniquely beneficial intervention.

Among women living with HIV, peer support has been repeatedly shown to be an accepted and valued social support intervention. Within Laura K. Beres *et al's* (2017) systematic review of non-specialist psychosocial support interventions for women living with HIV, nine studies met inclusion criteria, of which five had

interventions delivered or co-delivered by women living with HIV. Common features among studies with significantly positive results included having women living with HIV as intervention providers, information being delivered by a person rather than a computer, and “extensive grounding in theory and formative work to tailor the intervention to the target population” (ibid. p .6). These features resonate with the four main strategies employed within peer support interventions identified in previous qualitative research, and synthesised within Sokol and Fisher’s (2016) review: (1) trust and respect; (2) flexibility; (3) community partnerships; and (4) and user involvement and empowerment (Cortis, 2012; Flanagan & Hancock, 2010). Amongst these, ‘trust and respect’ was most consistently evidenced to have a significant effect, specifically in connection to participant retention (Sokol & Fisher, 2016, p. 7).

Beres *et al.* also note that, as their systematic review focused only on peer-reviewed articles, they did not capture unpublished interventions, “which may be more likely to be voluntary, locally-appropriate or sustainable without external support” (Beres et al., 2017, p. 7). *Given the common features of significantly positive studies identified within the review, this presents a potential gap in knowledge around the design of successful supportive services provided by non-publishing entities and individuals.* This is especially true within a UK context, as HIV social support services (including HIV peer support services) are predominantly provided by charitable or volunteer organisations.

A further gap is identified by Beres *et al.*’s (2017) regarding the limitations of evaluated outcomes. While interventions captured within the review focused on instrumental outcomes, the authors note that this often overlooked the complex and intersectional identities of the participants, often only supporting women within their

roles as expectant mothers or mothers, rather than as individuals (Beres et al., 2017, p. 6). In doing so, studies largely missed addressing key, holistic priority areas raised by women living with HIV themselves, as well as excluding the experiences of women who have not experienced motherhood or who are at a different stage of their lives.

The importance of developing a holistic understanding of service user experiences beyond instrumental outcomes has been noted within research on HIV peer support. Simoni *et al.*'s review highlights that studies that assessed the success of outcomes in ways that were not self-reported (e.g. biomarkers) were less likely to indicate efficacy (Simoni et al., 2011, p. 6). They concluded that:

“there may be some situations in which the more subjective measures are the only options or are more appropriate; for instance, in studies which are under-powered for biological outcomes or in which rich, qualitative data on potential explanatory factors or contextual information would be useful” (ibid.).

Given the financial and socioeconomic factors affecting service delivery and design for women living with HIV, a rich qualitative approach to research within this space is appropriate. For the purposes of Design, the generative collection of contextual information in which to inform practice is essential, making design approaches well-suited to this inquiry.

These reviews highlight two key gaps: (1) limited representation in the academic literature of work on voluntary or non-profit peer support services for women living with HIV in the UK; and (2) a paucity of research approaching HIV peer support services holistically, rather than through instrumental outcomes. *In this thesis,*

I build a case for supporting the design of community-based and sustainable digital peer support interventions.

While there is limited published research within this space, a notable exception is a 2016 study of a UK peer support service for women living with HIV that takes a holistic approach. In Jenny McLeish and Maggie Redshaw's study of Black African mothers' experiences of a 'Mentor Mother'¹⁵ programme in London, the authors found several areas in which peer support offered beneficial additions to clinical support. These benefits were often associated with the sharing of lived experiences by Mentor Mothers, to ground their support and advice, and understanding of the social contexts in which the women lived (McLeish & Redshaw, 2016). The mentored women who were interviewed expressed that difficulties involved with living with HIV were "intensified by poverty, poor housing, insecure immigration status, relationship breakdown and domestic abuse" (ibid. p. 7), a finding also reflected in other studies on Black African women living with HIV in England (Flowers et al., 2006; Tariq, 2013). Additionally, adhering to medical advice was complicated by a "culture of secrecy" around HIV, and associated anxieties in both social and religious contexts (McLeish & Redshaw, 2016, p. 7). By providing support sensitively from a standpoint of lived experience, *health advice and guidance from Mentor Mothers was more trusted than the same messages given by health professionals*. The efficacy of peer support to effectively convey HIV information and guidance has also been shown within mixed-methods clinical research (Cabral et al., 2018). In both cases, peer support effectively supported clinical services through individual support provided sensitively,

¹⁵ A 'Mentor Mother' is a specific form of HIV peer support in which women living with HIV mentor other women experiencing pregnancy, providing psycho-social support through and after their pregnancy journey (4MNetwork, 2021).

pragmatically, contextually, and by mentors presenting an embodied example of what it means to be living well with HIV.

Using McLeish and Maggie Redshaw's study as reference, *this doctoral work investigates both the current use of digital tools and services for peer support by women living with HIV in the UK, and the potential for further digital interventions within this space*. In order to contextualise my work within the broader discourse of digitally mediated HIV peer support, I will now provide a brief overview of the work within this space, before expanding on existing HCI research involving HIV broadly in the next subsection (2.1.4).

2.1.3.2 Digitally Mediated HIV Peer Support

The use of digitally mediated interventions (or eHealth) within Digital Health HIV care and prevention services has been an increasing field of inquiry over the past 15 years (Henny et al., 2018), (Nguyen et al., 2019), (Cooper et al., 2017), (Conserve et al., 2016), (Ronen et al., 2020), (Pellowski & Kalichman, 2012), (Taggart et al., 2015), (Tso et al., 2016), (Lockhart et al., 2021); including research on the use of mHealth¹⁶ interventions by women living with HIV in the United States (US) (Tufts et al., 2015). However, this research has primarily focused on specific health outcomes, such as adherence to medication, rather than other domains of self-management (such as those provided through social support, e.g. emotional, educational, instrumental support), or tailoring interventions to the needs of women (ibid.).

Recent intersectional research provides further insight into the impact of gender on reported use and willingness to use digital technologies for HIV-related purposes. Women living with HIV in Florida, US,

¹⁶ mHealth: eHealth interventions deployed via mobile devices, such as mobile phones.

reported greater use and willingness to use text messaging via mobile phone over other digital technologies¹⁷ for HIV-related purposes; and reported preferring to use text messaging on a mobile phone more than any other digital technology option in comparison to men (Lockhart et al., 2021). MSM¹⁸ living with HIV generally reported being more willing to use Internet or Apps on a mobile phone than women. The study concludes that mobile phones are most accessible for all participants, while highlighting intersectional differences in the use and willingness to use digital technologies. This study sheds light on the diversity of digital technology usage by people living with HIV and the authors recommend that digital HIV interventions be tailored to the preferences of potential users.

The use of eHealth interventions for peer support has been broadly shown as to be an acceptable means for HIV social support, as “patients living with HIV/AIDS seek more than just scientific facts or technical information whilst online,” (Mo & Coulson, 2014, p. 990) and digital technologies become increasingly embedded within daily life. In their recent literature review on digital HIV peer support interventions, Kesnet Ronen *et al.* (Ronen et al., 2020) report on the increasing global use of electronic communication platforms for peer support within HIV care provision. Their review attributes the increased use of digitally mediated peer support interventions to (1) digital technologies and platforms (such as social media) becoming more commonly accessible and used across the world¹⁹; (2) theoretical considerations, such as increased understanding of the ways in which peer experiences can inform better service delivery;

¹⁷ Including desktop, notebook, or laptop computers; tablet computers; apps on a mobile phone; or Internet on a mobile phone.

¹⁸ ‘MSM’ stands for ‘men who have sex with men’, a behavioural category widely used within HIV discourse.

¹⁹ With these increases for “digital connection with *networks* of people, rather than *individuals*... increasingly becom[ing] a norm” (Ronen et al., 2020, pp. 557-558).

and (3) practical considerations, such as the potential for eHealth to overcome some barriers to in-person services (e.g. confidentiality) and the potential for digital services to be more affordable to provide than in-person services²⁰.

Despite the increase in research involving digital peer support interventions, very little has been published on the use of digitally mediated peer support by women living with HIV. Ronen *et al*'s review foregrounds this limitation in extant research: only two of the 45 published articles and 12 ongoing projects reviewed explicitly focused on women (Blackstock et al., 2015; Hay et al., 2020b), one of which is an article published on one of my doctoral studies²¹. By contrast, 14 articles focused exclusively on eHealth peer support intervention usage by men. Considering that women make up the majority of people living with HIV globally (World Health Organization, 2014) the lack of representation of women in eHealth research on HIV peer support leads to a significant gap in knowledge. As the importance of tailoring services appropriate to the

²⁰ It is important to note that while this literature review included papers representing populations from various international countries, all papers from countries in the global south focused on eHealth usage either by youth at risk or living with HIV, or men who have sex with men (MSM), exclusively. I raise this to make note that while eHealth interventions are becoming more common, their usage within HIV services for women living with HIV is still limited in application globally.

²¹ Within this review, two studies focused on men who have sex with men (MSM) and trans women who have sex with men, however both covered the same digital intervention and only differentiated participants within their general demographic information as opposed to unpacking the impact of gender on experiences with the intervention (Hightow-Weidman et al., 2015; Muessig et al., 2014). Papers on eHealth interventions for any adult person living with HIV which included gender demographic information varied in gender distribution, often in relation to country: studies from China having under 5% women participants (J. Han et al., 2016; X. Han et al., 2018), studies from the United States or Europe having around 30% woman participants (Flickinger et al., 2017); and a study conducted with participants in various Arabic countries having 45.8% of posts made by women participants (Asiri et al., 2017). The remaining five papers on interventions for any adult living with HIV did not include gender demographic information (Chen & Shi, 2015; Cole et al., 2016; Coursaris & Liu, 2019; Shi et al., 2017; Wang et al., 2016).

needs of women living with HIV has been repeatedly presented, further understanding of these in relation to digitally mediated interventions would benefit the design of future tools and services. The necessity of this only increasing given the continual rise in global eHealth development and usage.

Data on the impact of gender on the use of digital peer support interventions by people living with HIV are limited and varied. Some report that women are more frequent users of online peer group forums (Mo & Coulson, 2010); some have found women living with HIV struggle to find support online when seeking it (Walsh et al., 2012); while others have found no strong correlation between gender and HIV eHealth peer support use (Longinetti et al., 2017).

Stronger correlations have been drawn between socioeconomic status and HIV eHealth usage, such as increased usage of the Internet for HIV health information being related to higher income (Kalichman et al., 2005) and HIV eHealth access divisions based on socioeconomic status (Marhefka et al., 2020)²². Taking into account the socioeconomic challenges encountered by women living with HIV in the UK, this highlights how the affordability of accessing digital tools and services should be considered when designing eHealth interventions for this user group.

Another association has been found between age and eHealth platform preference, with older participants more often using group emails or online forums compared to younger participants, who prefer social networking platforms (Longinetti et al., 2017). This correlation may be more nuanced however, as preference for online

²² Income, and by extension socioeconomic status, may be connected to gender through instances such as the lower rates of mobile phone ownership by American women living with HIV in comparison to men (Horvath et al., 2012).

services for older participants within Blackstock *et al.*'s study with women living with HIV was also affected by Internet experience, with older women with Internet experience viewing an online support group more favourably than those without (Blackstock *et al.*, 2015). As the majority of women living with HIV in the UK are aged above 35 years old this is another important consideration when designing acceptable digital peer support interventions.

While there are limited data available on the use of eHealth interventions specific to women living with HIV, available studies do offer insight. Authors Oni J. Blackstock *et al.* investigated the potential for online peer support interventions through their interview study with 27 Hispanic and non-Hispanic Black women living with HIV in New York City (Blackstock *et al.*, 2015), finding that women were supportive of the concept of connecting with peers via the Internet generally, as well as within an online support group. They recommended that hybrid interventions using both in-person and online methods may be best suited for women living with HIV, and that online services may be enhanced through increased online access for women as well as training in digital literacy and privacy (Blackstock *et al.*, 2015)²³. Additionally, Authors Stephanie L. Marhefka *et al.* have conducted several clinical studies on the use of a video conferencing behavioural intervention covering topics such as HIV-related stigma and negotiating safer sex for women living with HIV in the United States (Marhefka *et al.*, 2012, 2013, 2019). They found video conferencing delivery of the group intervention feasible and valued by participants (Marhefka *et al.*, 2013) and suggest that many women would be willing to use digital technology-based

²³ They had also identified potential issues related to trust, digital access and literacy, and general Internet privacy.

interventions regardless of their digital experience level (Marhefka et al., 2019)²⁴.

These papers present eHealth interventions as acceptable for women living with HIV in the United States and provide some insight into potential benefits and concerns about using digital technologies for peer support interventions. Common benefits of these interventions were shown largely in relation to the potential for peers to connect and provide reciprocal social support digitally, while repeating points of concern have arisen around trust, privacy, online security, confidentiality, digital access and literacy, and lack of experience with digital technologies. Despite these concerns, the majority of women from all studies were willing to engage with digital social support interventions, which was mainly related to the desire to give/receive social support rather than particular interest in digital technology as a medium (Marhefka et al., 2019). *The acceptability of digital peer support interventions expressed in these studies offers hope for further research in this space and a starting point for the design of appropriate Digital Health tools and services tailored for women living with HIV.*

It's important to note the scarcity of evidence-based standards for digital peer support interventions for adults provided by community, charity, or non-profit HIV groups and organisations. The leading HIV peer support provider in the UK, Positively UK, has highlighted the benefit of utilising digital technologies for peer support in addition to in-person services, allowing service users to choose options for support that meet their needs and preferences (Positively UK, 2017).

²⁴ Over the eight-year span of these studies the concerns voiced by participants remained common, and included both non technology-related (e.g. lack of interest in group-based services for women living with HIV) and technology-related (e.g. privacy, confidentiality, online security, and lack of experience with computers) issues that could affect the success of eHealth interventions (Marhefka et al., 2012, 2019).

While they provide substantial guidance on best practices for in-person peer support programmes, little is available on best practices for operating peer support programmes digitally.

Within the HIV sector, digital tools and platforms are utilised for peer support service provision (e.g., Terrence Higgins Trust, 2020), however their use remains under-reported and under-explored in research (Taggart et al., 2015). This includes research within the field of Human Computer Interaction (HCI), as covered in the next subsection (2.1.4). Responding to this gap in knowledge is crucial to the development of acceptable digital peer support interventions that are sustainable within the unstable financial reality of peer support provision in the UK.

2.1.4 HIV in HCI

In addition to the work on digital interventions within HIV discourse, the use of digital technologies within the lives of people living with HIV has also been explored in the HCI research field. Within the HCI field, most HIV-related research has focused on digital interventions for HIV prevention and health tracking, including interventions in education (Merrill et al., 2013; Sorcar et al., 2017), testing (Pendergrass et al., 2018), vlogging (Huh et al., 2014; Jindal & Liao, 2018), medication adherence (Marcu et al., 2016; Salib et al., 2018), and personal health tracking (Bussone et al., 2016).

Within this discourse there have been calls for digital HIV interventions to be individualised (Simoni et al., 2015; Singh et al., 2017) via factors such as cultural tailoring (Sorcar et al., 2017; Tufts et al., 2015). The importance of understanding and designing for the needs of individual users in relation to the sociocultural implications of gender has also been highlighted as a key factor in regard to the

accessibility and use of digital technologies by people living with HIV within HCI research, albeit limitedly (Natarajan & Parikh, 2013).

While there has been an increasing focus on women's health and wellbeing within HCI discourses (Balaam et al., 2015; D. Brown et al., 2014; Lazar et al., 2019; W. Smith et al., 2017; Young & Miller, 2019), very little relates specifically to women living with HIV. The underrepresentation of women as a specific user group within HCI HIV discourse is similar, if not lesser than, the attention given to women within broader HIV eHealth research.

In their study working with women living with HIV in Chennai, India in 2013, authors Meena Natarajan and Tapan Parikh describe how Digital Health projects have increasingly focused on the flow of information from the service provider to patient rather than its use, resulting in a prioritisation of efficacy, standardisation, and measurement within HCI research (Natarajan & Parikh, 2013). Differing from this approach, Natarajan and Parikh employed a feminist epistemological stance in order to explore “why information dissemination and standardization (sic) models often fail to lead to safer health practices” through qualitative work within an HIV NGO run by women living with HIV (ibid., p. 144). While the authors had intended their ethnographic fieldwork to inform the design of a digital information sharing platform, through the voiced experiences of women living with HIV they found that “[t]he issue was not so much a lack of available information around prevention and treatment, but an inability [for women] to use that information” due to gender-related sociocultural constraints (ibid., p. 145). Rather than concluding that eHealth interventions may be unacceptable to this group, Natarajan and Parikh instead highlight the potential for eHealth interventions to be better utilised to support affective aspects of healthcare, such as

supporting existing relationships and fostering new ones, through social services *such as peer support*.

Natarajan and Parikh's work also highlights not only how the interplay between gender and sociocultural context impacts eHealth use, but also identifies a larger issue: what is researched to inform the design of Digital Health interventions? In problematising "how the... prioritization of efficiency, standardization (sic) and measurement [in Digital Health research] neglect the affective and relational experiences that determine the spread of [HIV]," Natarajan and Parik foreground how the majority of research on HIV eHealth interventions can miss evaluating (and therefore addressing through design choices) the diverse effects of social factors on health (Natarajan & Parikh, 2013, p. 143).

Research into the social contexts within which people living with HIV access and use technology represents a small but growing area of inquiry in HCI discourse (Bussone et al., 2019; F. Maestre et al., 2020; Natarajan & Parikh, 2013; Oduor et al., 2019; Singh et al., 2019; Warner et al., 2018, 2019), however these works have not focused on peer or social support explicitly²⁵. These studies underline the importance of a more nuanced understanding of the social needs and concerns of participants in relation to eHealth interventions, outside of a platform evaluation, in order to better design supportive interventions.

In exploring the social needs and concerns of women living with HIV in the UK in relation to the design of digital peer support interventions, there is a further component to consider: how to do

²⁵ Recent quantitative research on messages exchanged on the online HIV forum POZ has suggested that emotional support was more frequently exchanged than informational support within a community of people living with HIV (Gao & Shih, 2019).

design research that considers social factors within the context of HIV social support service provision. I now expand on this question in relation to Design discourses in order to inform my approach to design praxis within this space.

2.2 Doing Design Research & Praxis

2.2.1 Introduction

“[A] decade of government disinvestment has meant many of us have lost our HIV support services, our women-only spaces, advice centres, counselling and mental health services, disability support, local authority support for housing, our domestic violence support services...

The safety net gets more and more threadbare.”

— Florence Obadeyi and Jane Shepherd, peer researchers
(Sophia Forum & Terrence Higgins Trust, 2018, p. 4)

In the previous section I provided an overview of research involving women living with HIV in the UK, highlighting the lack of and need for research engaging with how the lived experiences of women relate to their conceptualisations of digital tools and services. Women living with HIV report high levels of social support need, much of it largely unmet (Public Health England, 2020b), however these services have been repeatedly cut back in relation to changes in health policy and funding (Aduaka et al., 2018; Dalton, 2016; National AIDS Trust, 2016b). Simply put, there not enough services to meet demand. Additionally, digital interventions created and sustained by service providers within this climate are generally not represented within academic research (Beres et al., 2017; Taggart et al., 2015).

There is little purpose in designing digital tools and services if no one is able to deliver them, despite these services being so desperately needed. Whilst there is a lack of published research in this space, there is a wealth of untapped insight into how digital interventions have been designed and are currently being used by HIV service providers. In response to this, I adopted a Community-Based Participatory Design (CBPD) approach for my doctoral work; building on the existing expertise of HIV social support service providers and

the resources available to them to support responsible digital innovation.

Within this section I will establish a foundational understanding of this approach within Design (2.2.2), providing a conceptual basis to using it within this design research context. I then provide examples of CBPD practice within HCI health discourse using the concept of ‘infrastructuring’, or developing design works in relation to existing health provision infrastructures using collaborative approaches (2.2.2.1). I then link this approach to current movement towards a Fourth Wave research paradigm within the HCI field (2.2.3), shedding light on the positioning of my thesis within HCI and Design Research discourses.

2.2.2 Community-Based Participatory Design

As a relatively recent field emerging from Participatory Design (PD) (Simonsen & Robertson, 2012), Community-based Participatory Design (CBPD) extends beyond the historical grounding of PD within the workplace to consider the “social constructs and relations of groups in settings that can include, but go well beyond, formal organisational structures” (DiSalvo et al., 2012, p. 183). Within this context in HCI discourse, the democratic ideals of PD are positioned within communities, challenging the traditional division[s] of “‘designer’ and ‘users’... and ‘design’ activities as separate from an ongoing practice ([and also] technology use)” within the collaborative process (ibid., p. 203). Therefore, to conduct CBPD praxis is to challenge the role of the designer as a lone design expert within the design process; the designer is repositioned as a collaborator with design expertise, working in coalition towards shared and evolving design goals, informed and led by community interests and sustained by available resources.

This approach resonates with other politically-engaged research approaches used in Health research, such as Community-based Participatory Research (CBPR) and Participatory Action research (PAR)²⁶, where researchers are similarly repositioned as one of many experts working in coalition towards a common cause: “working **WITH** each other, not doing **TO** or doing **FOR** one another” (Kendall et al., 2017, p. 29). These approaches are typically utilised within marginalised or unequal contexts; they acknowledge lived expertise and community strengths; and they aim to work in coalition with communities to identify issues, make recommendations, define response plans, and implement interventions (Coughlin et al., 2017). CBPR has increasingly been used for HIV research, including for studies involving women living with HIV (Bird et al., 2017; Namiba et al., 2016; Stevenson et al., 2017). CBPR has been found to add value in such work especially for the meaningful involvement of underserved communities, and to enhance the quality of life and self-efficacy benefits of the resulting interventions (Bird et al., 2017).

A unique critical component of CBPR in relation to Health research is the tension between “academic expectations and utility” (Kendall et al., 2017, p. 24) — what emerges through the research process may stray from the initial plans as the work unfolds in pursuit of what is useful or meaningful for all collaborators. As CBPR is guided by its communities, there is always the potential for priority topics to shift in response to new needs; this kind of adaptive flexibility is uncommon in Health research and complex in methodological terms (Rothmann et al., 2016). When considered in relation to design research, this means CBPD work must also remain flexible to the needs of collaborators, and guided by communities. For example, a project

²⁶ Generally, CBPR entails conducting research with communities that result in insights or interventions, whereas PAR is research done through implementing insights or interventions.

looking at creating a mobile app to connect community group members may find that a paper newsletter sent through the post is more suited for their needs; a CBPD project would then adjust its focus to design for that new application. Flexibility and pragmatism are essential for community-based approaches to design research, as the outcomes (or artefacts) of research should be informed and led by community interests and their available resources, not what is considered most novel or innovative for academic discourse.

In both CBPD and CBPR, it is crucial to consider the assets that communities have available to them to support resulting interventions. Within the context of designing digital tools and systems, CBPD practice with community-based organisations has highlighted the common lack of available resources to support or sustain digital innovation (DiSalvo et al., 2012). This issue has led to an increase in assets-based approaches within community-based HCI research: focusing research on using what is available rather than identifying what is lacking (Wong-Villacres, DiSalvo, et al., 2020). This approach pursues sustainable innovation that may operate beyond the life of a particular project, as well as respecting and building on the capacities, strengths, and knowledge of users (Wong-Villacres, Gautam, et al., 2020). This approach challenges the limited understanding and utility of needs-based approaches to research, which often perpetuate stereotypes of marginalised populations rather than build towards effective change (ibid.). The utility and emancipatory benefits of asset-based ways of thinking have also underpin CBPR approaches in studies involving women living with HIV in the UK (Stevenson et al., 2017), complementing the activist call for the meaningful involvement of women living with HIV in research (Namiba et al., 2016).

CBPD's framing of novel artefacts as what works for a specific context/community may include adapting or adjusting products that already exist within research literature or commercial markets. This framing holds some tension with Interaction Design²⁷ discourse, which encourages research artefacts to innovate beyond what may be already published or commercially available (Zimmerman et al., 2007). It is *integral* to a CBPD approach that shared goals are pursued, which may involve the production of design artefacts that are limited to available assets; this is especially true within marginalised health contexts. It is therefore crucial that any resulting artefact be viable for actual use, which in turn may mean adapting technologies found within commercial markets. I note this tension to identify how CBPD is novel, not only in its methodological approach, but also in its artefacts as contributions to Interaction Design discourse—there are reasons why existing technologies (as currently configured) may not work, and it is illuminating to understand why that is through (re)designing something that does or appropriate alternatives.

The use of community-based approaches in both Design and Health discourses has arguably repositioned the designer-researcher as an expert among experts, challenging traditional notions of who has authorship over design/research decisions. However, this does not deny the importance of designer-researchers contributing their *unique* expertise to collaborative efforts. Ezio Manzini has highlighted this divisional fuzziness within PD practices, arguing that while all people hold the intrinsic ability to design (what he referred to as 'diffuse design'), there is still a distinction between this and design as an evolved skill or discipline ('expert design'), where one might be

²⁷ While I position myself as a communication designer, I engage with relevant subdisciplines (such as Interaction Design) because I am working within the HCI field.

“specially equipped with conceptual and operational tools to support designing processes” (Manzini, 2015, p. 38). Within this account I refer to designers within collaborative projects as ‘expert designers’ (as an extension to Manzini’s distinction between ‘diffuse’ and ‘expert’ design) in order to highlight the specialist design skills they may contribute to a collaborative project, rather than to argue who may qualify as a ‘designer’. In this way, a designer-researcher may bring unique expertise to a collaboration, but as one component of the overall team; supporting a design praxis in which the act of listening is as important as speaking.

The use of critical theories in relation to PD in HCI has delivered further insight into how to address this complex balance. Design Justice, for example, explicitly positions the designer as a “facilitator rather than expert” within community-based work, through their collaboration with those typically marginalised by design (Design Justice Network, 2018, p. 7). This repositioning has arguably been done to ensure that those most affected by design outcomes are continually centred; in turn, this promotes meaningful engagement rather than limiting how a designer may contribute to a collaborative project. However, Manzini has commented on the rising prevalence of ‘participation-ism’, compatible with this explicit approach, wherein designers play the role of removed, administrative facilitators within a formalised participatory process, rather than active contributing agents within a co-creative process (Manzini, 2016). Issues arising from this kind of removed positioning have also been noted by Cynthia L. Bennett and Daniela K. Rosner through their consideration of Critical Disability Studies and Feminist theories in relation to PD methods within HCI discourse. They note how empathetic methods used within HCI design processes with people living with disabilities are often abused as extractive or ‘check box’ exercises, rather than as means to support shared dialogue or

authorship (C. L. Bennett & Rosner, 2019). This concern can be traced back to John McCarthy and Peter Wright's initial positioning of empathy in HCI Design research, as a vehicle for dialogical understanding grounded in experience, in which they predicted that "if... empathetic methods become important [in HCI] they have to be understood and used in an appropriate way" (Wright & McCarthy, 2008, p. 644). While I will discuss empathy further in relation to methodology later on in Chapter 3 (3.2.1.1), it is important to introduce here, because establishing an 'appropriate way' to do collaborative design work is intrinsic to a CBPD approach, and at time of writing there is lively debate underway about the best means to facilitate this within HCI research.

2.2.2.1 Infrastructuring

CBPD discourse in HCI utilises a unique approach to the design of digital tools and systems. Defined by Susan Leigh Star and Karen Ruhleder as 'infrastructuring' (Star & Ruhleder, 1996; see also Karasti, 2014), CBPD approaches consider information technologies not as isolated 'applications' but in context of socio-technical relationships: "a relation between organised human 'doing' in social systems and [the] technologies that enable and support these ways of 'doing'" (DiSalvo et al., 2012, p. 202). This allows the activities of designers and users to be democratically considered as equally important, taking shape through an ongoing process of alignment between collaborators²⁸. This approach complements the assets-based purview and political aims of CBPD, opening the doors for all stakeholders to give insight and input, which in turn supports the design of more appropriate and sustainable digital interventions.

²⁸ DiSalvo et al note the similarity between this concept of 'infrastructuring' and Lucy Suchman's (Suchman, 1993) conceptualisation of 'artful integration' (DiSalvo et al., 2012).

Infrastructuring as used in CBPD also strongly connects with PD methodological developments in relation to socio-medical contexts, as founded as in the work of scholars Erling Björgvinsson, Pelle Ehn, and Per-Anders Hillgren at the Malmö Living Labs (Björgvinsson et al., 2010). As a design practice, Björgvinsson *et al.* have framed their approach as considering “design in, for and with agonistic public spaces as ‘thinging’... In this view, things are seen as socio-material ‘collectives of humans and non-humans’ through whom matters of concern or controversies are handled” (Björgvinsson et al., 2012a, p. 130). In taking this position, these scholars have focused more on the adversarial facets of PD *within* design processes and enactments, rather than artefacts. This has been purposeful; they have commented on the importance of asserting the additional socio-political considerations inherent within PD that are missing from proliferating collaborative design methods, such as design thinking (Björgvinsson et al., 2012b).

Within the context of healthcare and social support applications, the conceptual use of ‘thinging’ within PD discourse has informed work on the establishment of collaborations between existing social organisations and marginalised populations (Björgvinsson et al., 2012a); and the design of healthcare environments (Björgvinsson & Sandin, 2014). These works provide insight into how power dynamics between stakeholders affect social innovation enactments and offer novel means of illuminating the experiences of marginalised populations in those contexts. However, a gap in knowledge exists in how PD praxis operates within the creation of design outputs (e.g., artefacts) that operate independently within the everyday lives of users (e.g. eHealth interventions) for healthcare and social support that are made in coalition with marginalised users.

The use of PD concepts of ‘thinging’ or ‘infrastructuring’ in relation to the co-creation of artefacts for service provision is exemplified by the work of Christina N. Harrington within HCI discourse; her recent research utilises CBPD within Health contexts alongside marginalised populations in the United States²⁹. While not stated explicitly, Harrington has used the conceptual framing of infrastructuring within her co-design processes to inform the design of Digital Health interventions (Harrington et al., 2018) by building understanding about the conceptualisation of Digital Health technologies by marginalised users (Harrington et al., 2019; Harrington & Piper, 2018).

Within her recent article for ‘Interactions’ magazine³⁰ on Community-Based Health Design, Harrington offered insights from her research experiences to help “evolve the common narrative of marginalized groups away from challenges and disparities, and to acknowledge the ways in which Design should push for a more holistic narrative” (Harrington, 2020, p. 26). Through her analyses of both human ‘doing’ and technological ‘doing’, Harrington redefines ‘accessible technologies’ as “not just those [technologies] that are easy to interact with in relation to vision, hearing, and touch... [but] also those that consider culture, societal positioning, and economic status... consider[ing] all facets of what it means to obtain, own, operate, and maintain technology” (ibid., p. 27). Additionally, Harrington notes the importance of humanising narratives about marginalised user populations within HCI research involving health and wellbeing, as “[m]arginalised communities as a whole have typically been looked at as a problem that needs to be investigated

²⁹ Harrington’s published work involving health to date has largely focused on her design research on health perceptions with low-income African American older adults in the United States.

³⁰ ‘Interactions’ is an academic magazine publishing short articles involved with HCI discourse at large.

or solved [within HCI research]... [this] [d]amage-centered research reinforces the worst stigma about a population by painting a one-dimensional narrative of depletion, without acknowledging the aspects of identity that are valuable and unique” (ibid., p. 28). These insights resonate within the context of my doctoral work and resultant thesis; both in the multifaceted considerations of what it means for digital technologies to be ‘accessible’ for women living with HIV, and in the importance of community narratives for emancipatory progress within research.

Harrington’s work sheds light on how designers using CBPD praxes might co-create design artefacts for healthcare and social support that operate independently within the everyday lives of marginalised users (e.g., eHealth interventions). Her work highlights how designers working with marginalised communities must also consider how their research pushes towards humanising narratives rather than “damage centred research [that] reinforces the worst stigma about a population” (Harrington, 2020; Wong-Villacres, Gautam, et al., 2020) p.28]. This echoes the concerns of other CBPD practitioners within the HCI field, who have noted how needs-based (rather than asset-based) research approaches often perpetrate stereotypes of marginalised populations rather than building towards effective change (Wong-Villacres, Gautam, et al., 2020). These sensibilities for designing with digital technologies go beyond the process of designing or the applied use of the research artefact to also consider the broader accountability, responsibility, and ethics of design praxes within unequal contexts. This builds on Star & Ruhleder’s foundational concept of ‘infrastructuring’ (Star & Ruhleder, 1996) to critically consider how digital technologies actively affect the world around us through our socio-technical relationships with designed artefacts. Within HCI, this critically-informed perspective is characteristic of the emerging Fourth Wave HCI (Frauenberger, 2019) research paradigm.

2.2.3 Fourth Wave HCI

Christopher Frauenberger (2019) has described the current movement within HCI towards a Fourth Wave paradigm as 'Entanglement HCI'. He posits that "humans and their things are ontologically inseparable from the start... decentr[ing] the human as the sole source of activity and [elevating] the role of the non-human world from passive backdrop to human activity, to active contributors to relational action as it unfolds" (ibid., p. 21). This view lays bare how people and things are 'entangled' within socio-material arrangements, each inter-dependant on the other, making studying them separately a flawed pursuit. Frauenberger notes that this ontological movement is key in responding to the increasing calls for those involved in designing digital technologies to consider the accountability, responsibility, and ethics of this work as it continues to shape our world.

This Fourth Wave (Frauenberger, 2019) approach echoes the concerns and considerations of CBPD's 'infrastructuring' (Star & Ruhleder, 1996) and PD's concept of 'thinging' (Björgvinsson et al., 2012a) through its consideration of socio-materiality and the ethical implications of this entwinement. HCI designer-researchers using CBPD approaches within unequal contexts have highlighted how this may unfold, as damage-centred and needs-based research reinforces stereotypes and stigmatising beliefs about marginalised populations rather than build towards effective change (Harrington, 2020; Wong-Villacres, Gautam, et al., 2020). These insights highlight the importance of considering the socio-material and ethical impact of design research within marginalised and stigmatised health contexts (such as HIV). However, while previous CBPD discourse has raised the ethical implications of this for research *narratives*,

there is little HCI CBPD discourse discussing how this relates to designing research *artefacts*.

Thoughtful Interaction Design proponents Jonas Löwgren and Erik Stolterman have previously asked that interaction designers creating digital artefacts consider the socio-material impact of their work within their approach (Löwgren & Stolterman, 2007). Their work notes the responsibility of Design in “*shaping the world we live in by creating the conditions, opportunities, and restrictions that will make up that world*” (ibid., p. 11), echoing the socio-material considerations of Fourth Wave HCI (Frauenberger, 2019). However, while they call for designers to reflect on the ethical responsibility of their design praxes within their work, they do not engage with how these design processes or emergent artefacts may challenge or reinforce negative beliefs.

HIV-related stigma continues to negatively affect people living with HIV despite social and medical advancements (Auzenbergs et al., 2018; Sophia Forum & Terrence Higgins Trust, 2018). A national mixed-methods study conducted by the National AIDS Trust found that HIV-related stigma continues to exist and is felt to be deeply entrenched within the UK (National AIDS Trust & Fast-Track Cities London, 2021). By adopting a Fourth Wave (Frauenberger, 2019) perspective in this thesis, I take on additional considerations for how making design artefacts may challenge or bolster these negative beliefs within this context.

In summary, CBPD is novel within Interaction Design discourse through its methodological tenets and its contributing artefacts. Firstly, in methodological terms, designer-researchers work *with* (not ‘to’ or ‘for’) collaborators, repositioning themselves as an expert among experts. Within the doctoral work I took an approach informed

by DiSalvo (2012) and Manzini (2015, 2016), viewing the designer-researcher as an active agent within a collaborative relationship, with their role as collaborator being informed by the unique context of each collaboration. In this way the designer may contribute their expertise, as beneficial to the shared cause, while remaining responsive to (and respectful of) the expertise of others. Secondly, CBPD artefacts utilise an assets-based (Wong-Villacres, DiSalvo, et al., 2020) approach to design research, using resources available to communities to support sustainable innovation.

Both CBPD's concept of 'infrastructuring' (Star & Ruhleder, 1996) and PD's concept of 'thinging' (Björgvinsson et al., 2012a) embrace considerations for how socio-material interactions shape the world around us, illuminating the responsibility of Design in affecting these interactions. These considerations resonate with the current movement within the HCI field towards a Fourth Wave research paradigm. However, there is a lack of published insight on how this approach may inform design praxes involving Digital Health tools and services within stigmatised health contexts. Embracing Fourth Wave (Frauenberger, 2019) HCI Design research within a stigmatised health context I now turn to provide further contextual information on the concept of stigma and Design approaches that set out to change beliefs through making artefacts. I also introduce further Design-led Emancipatory approaches that have informed the development of my thesis.

2.3 Designing in Stigmatised Contexts

2.3.1 Introduction

“I will therefore follow in Delaprote’s assertion³¹: AIDS does not exist apart from the practices that conceptualize (sic) it, represent it, and respond to it. We know AIDS only in and through those practices. This assertion does not contest the existence of viruses, antibodies, infections, or transmission routes. Least of all does it contest the reality of illness, suffering, and death. What it does contest is the notion that there is an underlying reality of AIDS, upon which are constructed the representations, or the culture, or the politics of AIDS. If we recognise that AIDS only exists in and through these constructions, then hopefully we can also recognize the imperative to know them, analyze (sic) them, and wrest control of them.”

— Douglas Crimp (Crimp, 1987, p. 3)

In the previous section (2.2) I mapped how the conceptual and methodological foundation of my PhD thesis is informed by previous CBPD and PD research in HCI involving Health, and current movement in the field towards a Fourth Wave (Frauenberger, 2019) research paradigm. In doing so I raised the ethical importance of considering the socio-material implications of design research within stigmatised health contexts. Material artefacts actively shape the world around us, giving research artefacts the potential to bolster or challenge negative beliefs (such as stereotypes or stigma). While this issue has been raised in CBPD research within the HCI field in relation to research narratives (Harrington, 2020; Wong-Villacres, Gautam, et al., 2020), a gap in knowledge exists around how this issue relates to design praxes—how negative beliefs may affect the

³¹ “I assert, to being with, that ‘disease’ does not exist. It is therefore illusory to think that one can ‘develop beliefs’ about it to ‘respond’ to it. What does exist is not disease but practices” – Philosopher François Delaporte, speaking about the conceptualisation of Cholera in 1832 (Delaporte, 1986, p. 6).

designed form of research artefacts, which in turn communicates these beliefs to users.

As discussed in my Introduction (1.1), Design has been involved within the communication of HIV since the ‘AIDS Crisis’ of the 1980s. Communication Design works have affected public and personal conceptualisations of what HIV is and what it means to live with it, for better or worse. The opening quotation of this section highlights the importance of understanding what these beliefs are and how they are communicated in order to respond to them. HIV-related stigma continues within the UK (National AIDS Trust & Fast-Track Cities London, 2021), including through discrimination within healthcare provision (Auzenberg et al., 2018; Sophia Forum & Terrence Higgins Trust, 2018), despite social and medical advancements. HIV interventions cannot be purely concerned with function alone—the historical spectre and ongoing reality of HIV-related stigma *demands* that we wrestle with the social representations, conceptualisations, and politics of HIV as a ‘disease’ as well. This adds an additional layer to any design work involving digital interventions for people living with HIV: how will Digital Health interventions challenge or reinforce conceptualisations of HIV as a stigmatised illness? This is a key consideration for designing for peer support services, as addressing internalised stigmatising beliefs in service users is an integral component of increasing wellbeing in service users (Simoni et al., 2011).

In doing CBPD work within this context, it is of ethical importance for me to reflect on how design artefacts created through my design praxis may bolster or challenge these beliefs. As raised in an earlier subsection (2.1.3.2), existing research on Digital Health interventions for people living with HIV has largely focused on instrumental

outcomes³² rather than user perception or wellbeing. These studies arguably do not capture what the designed *form* of digital tools and services communicate to users beyond these outcomes. In looking at the design of digital interventions for peer support specifically, this presents a gap in understanding of how the form of digital artefacts may help or hinder the therapeutic services they mediate. In taking a CBPD approach to my doctoral work, in which I position myself as an 'expert' designer (Manzini, 2015) working in coalition with women living with HIV, I will be influencing the form of emergent research outputs. As a communication designer I have expertise in making artefacts that communicate intended meanings through their form, however my understanding of HIV is limited and shaped by my lived experience. As a cisgender White, Canadian woman not currently living with HIV, my experience will differ from many of my collaborators; there is a risk that my own beliefs may unintentionally colour emergent artefacts due to my involvement in their creation. In this way it is key to consider how the material language used by artefacts is informed by design praxes, and how this is shaped within collaborative design works³³.

In the following subsections I will first provide a brief overview of the concept of stigma (2.3.2), its conceptualisation within the lives of

³² Such as medication adherence or HIV prevention.

³³ It is important to briefly establish that this relational approach between artefacts and surrounding society is closer to symbolic interactionism than semiotics, a similar empirical study of symbols largely based in linguistics and the arts that is more common within Design discourse. While semiotics focuses on how a symbol is understood and used within a society (The Editors of Encyclopaedia Britannica, 2020), symbolic interactionism looks at how symbols are used by individuals to express and understand meaning in their lives. In other words, while semiotics focuses on the symbol as the point of inquiry, within symbolic interactionism symbols are just a fulcrum to the true focus of study: interaction as meaning making. As women living with HIV represent a diverse demographic within the UK, and as such may largely differ in term of shared symbols, I take a symbolic interactionist approach rather than a semiotic one within this thesis. In this way I will be focusing on how designed artefacts are informed by and communicate meaning (beliefs) on an individual level rather than characterising artefacts as symbols used within broader society.

women living with HIV (2.3.3), and its conceptual extension through Critical Disability Studies discourse (2.3.4). I will then discuss how this context relates to Emancipatory HCI (2.3.5) and Design-led Emancipatory (2.3.5.1) discourses, highlighting the need for a craft perspective of Design-led Emancipatory HCI. From this framing I then present a rhetorical view of Communication Design as a novel design praxis for Design-led Emancipatory HCI that utilises this conceptual approach (2.3.6); providing supporting examples of comparable approaches (2.3.6.1) and empathetic design practices (2.3.6.2) within HCI discourse. I then introduce examples of this conceptual approach has been used to emancipatory effect within communication design works involving HIV (2.3.7), informing and inspiring my novel approach and positioning HIV Health Design as a political design praxis. From this standpoint I then position this work within Adversarial Design (2.3.8), and offer examples of Communication Design works that embody an Adversarial Participatory Design approach (2.3.8.1) in order to position my approach to this doctoral work in relation to existing Design discourses and practices.

2.3.2 Stigma

The concept of stigma is widely attributed to sociologist Erving Goffman. In his foundational work, Goffman defines stigma as “an attribute that is significantly discrediting” which reduces the person who possesses it in the minds of those who share the understanding of the attribute being discredited (Goffman, 1990, p. 13). In this way, stigma is not an individual process, nor a static concept: rather it is a constantly changing social process that Goffman explains should be “...seen [in] a language of relationships, not attributes” (ibid., p. 13). As a *social* process, stigma can be experienced by an individual both internally (internalised stigma), when the individual conceptualises themselves to be negatively regarded socially as owner of a

discredited attribute; and externally (enacted stigma), when others act negatively towards the individual as owner of a discredited attribute. As a *changing* social process, discredited attributes, and the reason(s) why they are discredited, are not inherently defined, but rather formed socially through shared beliefs.

2.3.3 HIV-Related Stigma and Women Living with HIV

Women living with HIV are uniquely affected by HIV-related stigma due to intersecting gender-based social inequalities (Amin, 2015). Previous HCI research has highlighted the impact of these intersections for women living with HIV; both with regard to the sociocultural implications of gender in India (Natarajan & Parikh, 2013); and in the US in the form of societal assumptions of promiscuity and/or recreational drug use in relation to a woman living with HIV (F. Maestre et al., 2020). The differences between the intersectional relationship between gender and HIV within these separate cultural contexts also highlight the changing and situated nature of stigma—it is created and shaped by the social context it exists within.

The stigma that women living with HIV face has been shown to contribute to poor mental health, including depression, associated issues such as low self-esteem, and reinforcing pre-existing gender-based social inequalities such as Gender-based Violence (GBV) globally (Orza, Bewley, Logie, et al., 2015). This has led researchers in the field to position stigma and discrimination against women living with HIV as GBV (Orza, Bewley, Chung, et al., 2015). These concerns are reported by women living with HIV in the UK. Within the 'Invisible no Longer' report, over half (58%) of women had experienced violence or abuse due to their HIV status, half of whom were then unable to access support for this (49%), and a third of whom could access 'some' support (31%) (Sophia Forum & Terrence

Higgins Trust, 2018, p. 56). Experiences of violence and abuse within healthcare settings was also reported to have increased after women were diagnosed with HIV (*ibid.*).

The concept of stigma in relation to women living with HIV in the UK has most often been explored with regard to healthcare. The 2019 Public Health England report on the experiences of women living with HIV revealed that 21% of women “worried about being treated differently to other patients due to their HIV status”; 13% had “avoided seeking healthcare when they had needed it because of their HIV”; and 7.3% “felt that they been refused healthcare, or their medical procedure had been delayed, due to their HIV status” (Public Health England, 2020b, p. 44). These findings were echoed by ‘Invisible No Longer’, wherein women expressed that they would avoid or delay accessing health services due to worries about how they would be treated because of their HIV status; 31% reported they had experienced such negative treatment within the past year (Sophia Forum & Terrence Higgins Trust, 2018, p. 53)³⁴.

While women living with HIV in the UK report experiencing both enacted and internalised stigma (Doyal & Anderson, 2005), internalised stigma has been reported at a higher rate (StigmaSurveyUK, 2016). Concerns over the implications of sharing information about HIV status has also been reported by women living with HIV in the UK, with 16% of women living with HIV reporting not

³⁴ Higher percentages of negative treatment within healthcare settings are reported by women living with HIV outside of London (Sophia Forum & Terrence Higgins Trust, 2018). This resonates with the findings of Maestre *et al.*'s work with people living with HIV in the United States, where participants from developing countries or those recruited from rural areas reported more experiences of enacted HIV-related stigma, including within healthcare settings (F. Maestre *et al.*, 2020). While UK healthcare locations outside of London may not be considered ‘rural’ *per se*, there are differences within HIV services provision, largely in relation to funding and service population, that support better HIV care provision within London in comparison to other areas.

having shared their HIV status with anyone outside of a healthcare setting compared to 11% of men (A. Brown et al., 2019, p. 44). Responding to the issue of stigma is difficult, given that it is an ever-changing social process created and upheld through interaction with various social contexts. *However, peer support interventions have been shown to be effective in addressing internalised stigma and HIV-related stigma (such as social isolation) (The National AIDS Trust, 2016b).*

In considering how the stigma experienced by women living with HIV specifically differs from other forms of HIV-related stigma it is also important to consider the impact of biographical disruption on women diagnosed with HIV when in older age.

2.3.3.1 Biographical Disruption and Women Living with HIV

On being diagnosed with HIV, women have been reported to experience biographical disruption (Doyal & Anderson, 2005). First noted by sociologist Michael Bury in 1982, biographical disruption is defined as an interruption to “the expectations and plans that individuals hold for the future”, requiring “a fundamental rethinking of the person’s biography and self-concept” (Bury, 1982, p. 169). This has become a key sociological concept within the study of chronic illness and has since been expanded upon, with evidence arguing that “the context of someone’s life has a strong bearing on how disruptive a chronic illness will be” (Barry & Yuill, 2016, p. 176). As HIV has shifted from a life-limiting disease to an LTC following medical advances (Deeks et al., 2013), this is an important consideration within the sociological discourse on HIV. However, this shift has been shown to have little to no impact on the levels of stigma (and its enacted form, discrimination) reported by women living with HIV in other western countries, such as Canada (Kaida et al., 2015).

Within his review of the literature on biographical disruption, Williams (2000) suggests that the onset of chronic illness can also be seen as continuity when the illness is seen as 'normal' in relation to age and class. Alternative approaches to biographical disruption in the context of HIV as an LTC specifically have been presented. Carricaburu and Pierret (1995) report on how gay men living with asymptomatic HIV report biographical continuity, rather than disruption. In this case, participants shared that their HIV diagnoses had reinforced their sense of political identity as gay men, and therefore saw the diagnosis as affirmation rather than disruption. As HIV is not commonly attached to an identity of 'womanhood', this could provide insights into how an HIV diagnosis can be uniquely disruptive to women.

Alternative experiences of biographical disruption have been shown in research involving women living with HIV specifically. In their sociological study involving women living with HIV in South Africa, Wouters and De Wet (2016) found that contextual factors (such as the high prevalence of HIV in South Africa, financial concerns, and the success of medical treatment in managing HIV) rendered a diagnosis of HIV less disruptive than in other contexts³⁵. However, while not as disruptive to a participant's own sense of biographical narrative, participants reported that HIV *did* impact how they were perceived by others, such as when sharing their HIV status at work or to others in new relationships. UK-based research reports similar concerns about HIV in relation to interpersonal communication, with

³⁵ This has been linked to the work of Pound *et al.* (1998) involving the biographical disruption of older people after experiencing a stroke. They found that "the context of a hard-lived life was crucial in shaping their biographies prior to the onset of their illness... disruption[s] that had nothing to do with illness, such as poverty and economic hardship were the main disrupters in their lives before they experienced a stroke" (Barry & Yuill, 2016, p. 177).

fewer women than men sharing their experiences of living with HIV with others outside of health contexts (A. Brown et al., 2019).

Women living with HIV report unique experiences of HIV-related stigma, both through the consequences of HIV-related stigma and the effects of biographical disruption, in comparison to gay men. This aligns with stigma as a contextual and socially evolving phenomena, highlighting the importance for responses that are tailored to women's specific needs³⁶.

Recent HIV discourse in HCI has begun to consider the interactions between enacted stigma and technology use by people living with HIV in the US through the work of Juan F. Maestre *et al.* (2020). While the authors stress that their findings on intersectional issues should be considered with caution given their limited sample, their study does highlight both the importance of greater representation of women within research and the need for digital technologies to adapt to intersectional needs (F. Maestre et al., 2020). However, while their research has focused on the potential for digital interventions to support individuals in 'coping' with stigma, I am more interested in how stigma relates to the design and usability of digital interventions in existing HIV social support service delivery for women living with HIV in the UK. In using this approach, I take on additional consideration of how *the design of digital HIV peer support interventions themselves* holds the potential to support or challenge existing stigmatising beliefs within both design process(es) and output(s)³⁷.

³⁶ As stigma is not an illness but a social understanding, it is then key to understand how to affect that social understanding, to affect what is considered 'normal', rather than solely consider it as a pathological issue that can be 'treated' with medical intervention.

³⁷ Within their work on videoconferencing peer support interventions for women living with HIV in the United States authors Marhefka *et al.* allude to this approach, stating that while "some researchers have suggested that delivering healthcare interventions via e-health modalities may reduce stigma... it remains

My engagement with stigma is informed through both my experience as a communication designer and through my positioning as a feminist researcher³⁸, prompting me to respond to the responsibility of Communication Design within the shaping of stigma as a socially created and upheld belief. As designed objects and experiences play a role within individual and social meaning-making, I feel an ethical pull to ensure that my design praxis pushes towards possible, positive futures *in addition* to understanding how lived experiences of HIV stigmatisation and other social inequalities relate to the design of digital peer support interventions. As I myself do not live with HIV, I also face additional ethical consideration for how I as a designer effect both service delivery and service users through my research activities and outputs, when I myself would not currently be personally affected by service change, nor hold personal lived experience of HIV-related stigma beyond understanding the concept itself through being in the world.

In order to both consider the intersectional needs of women living with HIV presented within previous research and methodologically support ethical design praxis within this space, I turn to briefly discuss how Goffman's concept of Stigma has been expanded

to be seen if such stigmatized (sic) conditions could be helped or hampered by the growing trend of e-health" (Marhefka et al., 2019, p. 511).

³⁸ I position myself as a feminist researcher in relation to both my use of feminist theories and practices (e.g., intersectionality, positionality) within my work and my personal socio-political beliefs (e.g., pursuing social and legal equality for all). I do not identify with one specific type of feminism due to the intersection of feminist theories (e.g., intersectional feminism) and compatible critical theories (e.g., critical race theory, critical disability theory, queer theory) in both my beliefs and practices. By self-identifying myself as a 'feminist researcher' I aim to highlight my use of critical theories within my design research praxes; underscore the influence of my socio-political beliefs in prompting me to seek emancipatory change when faced with social injustice(s); and connect my work to other feminist research within the interdisciplinary space of my doctoral work.

through Disability Studies, and how this has informed my methodological approach.

2.3.4 Critical Disability Studies on Stigma: Moving Beyond Goffman

HIV is a virus located within the body that affects both (1) physical wellbeing; and (2) one's ability to move through the world due to social structures and attitudes towards how one's body (and by extension, personhood) is "meant" to operate. In this way, HIV can be viewed through the lens of a social model of disability, where living with HIV may be disabling due to societal structures and attitudes³⁹. This view is supported by evidence that HIV stigmatisation continues within the UK despite medical advances (National AIDS Trust & Fast-Track Cities London, 2021). HIV-related stigma is not a result of HIV itself; instead it is a product of the social construction of HIV, what it means to live with it, and the design and practices of the world based on those understandings.

The social model approach to disability originated within the disability social justice movement in the US, led by the Union of Physically Impaired Against Segregation in 1975 (Union of the Physically Impaired Against Segregation, 1975); and has since been further formalised by Vic Finkelstein (Finkelstein, 1980) and Mike Oliver (Oliver, 1990), and then codified (Hasler, 1993) and defined within Disability Studies (Shakespeare & Watson, 1997). Disability studies as an academic discourse has similarly evolved in response to activist work, shifting aspects of the discourse from the Social Sciences to the Humanities (Brune, 2014). This move is in part affected by the historical context wherein Social Sciences linked the

³⁹ Rather than a medical model approach, where HIV is disabling due to its relationship to physiology alone.

concept of disability to deviance⁴⁰, as in Goffman's work on stigma, and activist criticism of the discourse's focus on academic debate rather than progressive action in response to identified inequalities (Oliver, 2013)^{41 42}. Contemporary Disability Studies has repeatedly advocated for the pursuit of affectual change within academic discourse for marginalised populations, and has cautioned about the power imbalances perpetuated by ignoring the discourse's inherent critical, activist components. This has historically been communicated through the activist call for "nothing about us without us," placing people living with disabilities at the heart of discourse about them in order to ensure emancipatory change is pursued.

In response to these developments, Disability Studies discourse within the Social Sciences has broadly adopted a critical but appreciative stance towards Goffman's conceptualisation of Stigma (Brune, 2014; Garland-Thompson, 2014; Love, 2014; Schweik, 2014; Titchkosky, 2014). Sociologist Sara E. Green has presented the work of Spencer Cahill as an example of how Sociological practice can extend beyond Goffman (Green, 2016)⁴³.

⁴⁰ Social science approaches have been critiqued within Critical Disability Studies for doing more to disable "than interrogating the causes of disablement in empowering ways" (Green, 2016, p. 44), as raised by disability scholar Tanya Titchkosky (Titchkosky, 2000).

⁴¹ This echoes the critiques of damage or need-based research by CBPD researchers within HCI discourse, as discussed in a previous section (2.2.2).

⁴² In the UK specifically, Mike Oliver (an instigator of the social model) has discussed how the social model approach has been significantly weakened in the UK through academic debate rather than action, and how this has, in turn, negatively affected reforms to the provision of benefits and services for disabled people since the 2008 economic downturn (Oliver, 2013). The negative effects of financial austerity measures have also been raised within HIV service provision for women living with HIV in the UK (Aduaka et al., 2018; Sophia Forum & Terrence Higgins Trust, 2018).

⁴³ Cahill was critically appreciative of Goffman (S. Cahill, 1992, 1994, 2004) and similar to Goffman did not consider himself as one who specifically studied disability but rather social interactions at large.

Green presents two major difference between Cahill's and Goffman's works: (1) Cahill's appreciative knowledge of his participants, approaching his research from the standpoint of "talking [not] about 'we the normals' [but] about 'us the strange'" (Green, 2016, pp. 50-51)⁴⁴; and (2) that Cahill co-authored his works on disability with Robin Eggleston, his student who inspired and collaborated with him on his work on the experiences of people who use wheelchairs as a peer researcher (S. E. Cahill & Eggleston, 1994)⁴⁵. In approaching differences in lived experience from the standpoint of *all* social interactions being strange, Cahill supported critical consideration on *why* certain interactions took place and *how* they pragmatically affected the lives of his participants. This allowed for understanding that could inspire constructive action and empathy, rather than merely reinforcing perceptions of specific traits as stigmatised.

From Green's conceptualisation of Cahill's sociological approach as a valuable extension of Goffman's work on stigma and disability, three key considerations for research involving stigmatised populations emerge: (1) working alongside those with lived experience as equals within academic inquiry and processes (such as co-authoring papers); (2) remaining aware of one's own privileged position as a non-member of a marginalised group without lived experience, if relevant⁴⁶; and (3) utilising research to create empathy

⁴⁴ Cahill's ability "*to make the familiar 'strange'...[and] make the strange even stranger*" has been presented as a key difference in his approach, and one of unique academic merit within sociological discourse (Lofland, 2007, p. 468).

⁴⁵ In contrast, Goffman's approach to describing lived experience of disability been argued to "anticipat[e] that both reader and researcher are "normal." Normals are a "we" that includes Goffman, his imagined readers, and all others who do not depart negatively from normalcy," creating a stigmatising dialectic within research involving people living with disabilities conducted by those not (e.g. us/them) (Titchkosky, 2000, p. 204).

⁴⁶ Within HIV discourse, the first two of these key considerations have been discussed and advocated for within the work of Angelina Namiba et al (Namiba et al., 2016) in calling for the meaningful involvement of women living with HIV and AIDS (MIWA) in research. The authors also note the emancipatory importance of

and understanding of the lived experiences of others, supporting the reader to reflect on the phenomena without recreating a stigmatising dialectic (e.g. ‘normal’/stigmatised), and supporting effectual change. These considerations align with a CBPD approach and Fourth Wave (Frauenberger, 2019) sensibilities: conducting research in true collaboration and coalition with affected communities; repositioning designer-researchers as an expert amongst experts; and viewing research outcomes (e.g., artefacts) as means to positively affect the world around us⁴⁷.

In positioning design research and praxes as a means to change the world around us, the activist intent that Critical Disability Studies induces work involving HIV-related stigma with links this approach to Humanistic discourse in HCI.

2.3.5 Emancipatory HCI

Authors Jeffrey Bardzell and Shaowen Bardzell position the goals of Humanistic HCI as being “in contrast to the scientific normative goal of objectivity in service to truth... [instead] commit[ed] to a normative goal of justice and right action, which necessarily unfolds with subjective agency” (J. Bardzell & Bardzell, 2015, p. 52)⁴⁸. The

women being involved as peer researchers in order to support further control and ownership of the academic discourse(s) that affect their everyday lives.

⁴⁷ HCI research has had a similar development within its approach to conducting research involving users living with disabilities. Disability studies was first introduced in the HCI field through the assistive technology studies of Jennifer Mankoff, Gillian R. Hayes, and Devva Kasnitz (Mankoff et al., 2010); their work draws from Disabilities Studies discourse to call for the active involvement of disabled people within assistive technology research about them. However, it has been noted that since their publication accessibility technology topics are still predominantly researched using a medicalised approach, counter to the goals of Disability Studies (Spiel et al., 2020).

⁴⁸ This commitment is shared across the diverse work captured within Humanistic HCI discourse, including humanistic work explicitly based within critical theory (e.g. HCI work involving Critical Race Theory (Ogbonnaya-Ogburu et al., 2020), Queer Theory (Spiel et al., 2019), and Postcolonial Computing (Irani et al., 2010), and in work positioning critical theory in relation to HCI research methods (e.g. ‘troubling’ (Light, 2011)).

involvement of sociocultural activism within HCI research is seen as Emancipatory HCI; a subcategory of Humanistic HCI defined by Bardzell and Bardzell as “any HCI research or practice oriented toward exposing and eradicating one or more forms of bondage and oppression, including structural racism, poverty, sexual repression, colonialism, and other forces/effects of the hegemonic status quo” (J. Bardzell & Bardzell, 2015, p. 115). Bardzell and Bardzell highlight the promise of an Emancipatory HCI practice in “help[ing] HCI practice [to] stop chasing the computer as it reaches out and start pushing it—pushing the computer towards preferred futures” (J. Bardzell & Bardzell, 2015, pp. 139-140). This sentiment echoes Frauneberger’s conceptualisation of current movement within the HCI field towards a Fourth Wave research paradigm that “re-directs our moral deliberations about desired futures from questions of impact to questions about who we want to be” (Frauenberger, 2019, p. 21).

Emancipatory HCI is identified as holding two distinguishing impulses: the hermeneutic impulse, to interpret and expose forces that inhibit one’s freedom; and the speculative impulse, to envision a future reality in which said forces have been eradicated (J. Bardzell & Bardzell, 2015)⁴⁹. In considering the relationship between Design and Emancipatory HCI, Bardzell and Bardzell identify alignment with various design traditions, including PD and PAR; noting that these traditions “so deeply intertwine social scientific, design, and critical sensibilities and practices that it seems like a fool’s errand to even attempt to analyze (sic) them separately” (ibid., p.123). As this is a Design Studies doctorate programme, I will now turn to contextualise my research subject within the *Design-led* Emancipatory HCI discourse.

⁴⁹ It is the speculative impulse specifically that demarcates this approach from a scientific one, as speculation need not be derived from broadly accepted fact exclusively.

2.3.5.1 Design-led Emancipatory HCI

Jeffrey and Shaowen Bardzell describe Design-led Emancipatory HCI as “typically using design methodologies to speculate about alternative futures that critique the present and offer aspirational images to work towards (e.g., in critical design) and/or reconfigures design methodologies themselves to better position design as an emancipatory practice (e.g., participatory design and value-sensitive design)” (J. Bardzell & Bardzell, 2015, p. 122). However, in attempting to locate my own design praxis within Design-led Emancipatory HCI discourse, neither of these categories are explicitly fit for purpose.

As one working within the context of designing for HIV support service delivery during a period of austerity with a marginalised user group, to focus on generating ‘aspirational images’ without application seems like a waste of resources that would be better directed towards the design and development of feasible services. Why present speculative examples when you could instead design emancipatory, fit-for-purpose outputs? Equally, to focus on Design methodologies alone, rather than in combination with design practice (e.g. praxis), would remove the impact of a designer (as an expert design practitioner) being involved within co-creative activities; potentially stealing attention from the impact of the emergent artefacts. As designers, we make things, so why isn’t there more focus on those things (and the processes of making them) as *themselves* being in service to the participants who we collaborate with within Design-led Emancipatory HCI?

Reflecting on these questions, I have pivoted away from investigating how digital interventions for peer support might help women living with HIV ‘cope’ with stigmatising experiences (such as with the

approach taken by Maestre et al. (2020)), to instead consider how Design (as process, outputs, and positionality) might better serve the emancipatory goals identified by women living with HIV, through the design of digital peer support interventions. This approach utilises the entwined hermeneutic and speculative considerations of Emancipatory HCI by (1) highlighting how HIV-related stigma impacts the design and use of digital peer support interventions; while (2) pursuing a design praxis that pushes towards possible futures, as advocated for within CBPD, Critical Disability Studies, and peer-led HIV discourses. I present this distinction not to argue that this approach is ‘more emancipatory’, but rather that these dual considerations are necessary in order to fully utilise the unique benefits of a CBPD approach.

In taking this approach, my work aligns closely with a *craft perspective* to Design-led Emancipatory HCI, wherein “the interrelation between the [making] process and knowledge production can inform HCI... through embodied engagement”—a praxis in which making and what is made are entwined within knowledge production (Frankjær & Dalsgaard, 2018, p. 481). As the crafted form of eHealth interventions is often limited to its embodiment within a device (e.g., on a screen), *I take a craft perspective using Communication Design praxis as a means to advance a Fourth Wave (Frauenberger, 2019) Interaction Design discourse within HCI.*

Synthesising my review of multiple bodies of work, I conceptualise HIV-related stigma as a socially contingent phenomena affected by design processes and outputs, with echoes of Critical Disability Studies’ discussion about the effect of academic practices on the conceptualisation and treatment of disability. As such, designing outputs in *response* to HIV-related stigma alone, rather than directly

challenging this dominant narrative, risks *reinforcing the shared social understanding that HIV is something to be stigmatised*. When working with emancipatory intent, this isn't good enough.

Similar issues have been raised within Design discourses involving disability. Specialising in Inclusive and Assistive Technology Design, Graham Pullin notes that traditional Product Design approaches that fail to recognise this emancipatory intent regarding disability have designed interventions to be as invisible as possible, potentially reinforcing a perception that Disability is something to hide or be ashamed of (Pullin, 2009, p. 15). Design and Critical Disability Studies scholars Elizabeth DePoy and Stephen Gilson have also approached this concept more broadly through the conceptual and literal branding of disability as 'abnormal' via designed products, iconography, architecture, and policy; DePoy and Gilson noting how the subsequent pathologising of difference through some designed medical interventions perpetuates inequality while financially benefitting from it (DePoy & Gilson, 2014). Whilst this idea has been broadly explored within the context of design for physical and cognitive impairments, there has been little discussion about how this relates to socio-political narratives of HIV within digital outputs. Design-led Emancipatory HCI outputs for HIV should address the needs and concerns of those living with HIV, such as the violence and discrimination informed by HIV-related stigma, whilst also seeking to understand how design processes and artefacts can promote emancipatory change in how HIV is considered in relation to these issues.

I now turn to present my background research on Communication Design praxes using a rhetorical analysis of Design (2.3.6). I position this design praxis in relation to comparable design approaches (2.3.6.1) and practices (2.3.6.2) within the HCI field. Following this I

provide examples of Communication Design praxes using this approach for emancipatory effect within the context of HIV (2.3.7), before relating this approach to Adversarial Design discourse within the HCI field (2.3.8 - 2.3.8.1). In doing so I shed light on how my approach builds on these existing discourses in pursuit of a craft perspective on CBPD praxes for Fourth Wave (Frauenberger, 2019) HCI discourse involving stigmatised health contexts.

2.3.6 A Rhetorical View of Communication Design Praxis

I have previously presented the perceived benefits for CBPD approaches, whereby the designer works in coalition with the audience or user rather than as isolated expert, in relation to both Design-led Emancipatory (J. Bardzell & Bardzell, 2015) and Fourth Wave (Frauenberger, 2019) discourses. Developments within Communication Design resonate with these discussions.

Communication Design has developed as a discipline from a practice relying on the intuition of the designer alone to one focused on creating empathy with the desired audience(s) (Forlizzi & Lebbon, 2002). This has been attributed to the growing diversity of audiences, for which a homogenous, shared language of communication does not exist. Women living with HIV are a diverse and geographically dispersed population in the UK. This diversity brings with it a breadth of experience, manifesting in different beliefs, language, and truths. In order for Communication Design to be effective, it must appropriately respond to the plurality of experience among members of this 'audience'.

Communication Design has evolved to establish a *rhetorical analysis of Design* in response to the growing diversity of audiences and subsequent lack of a homogenous, shared language. This relationship has been defined by Design researcher Ann C. Tyler as

one in which the audience is “a dynamic participant in argument” (Tyler, 2006, p. 38). In this view, designers do not aim to make statements via grammatical structure or semiotics, but rather facilitate a dialogue through “the use of existing beliefs to induce new ones... [which] contribute to maintaining, questioning, or transforming social values through argument” (ibid., p.38). This dialogue is then used to achieve the goal(s) of the design work, which can include inducing action, education, or facilitating an experience. This approach also demands additional ethical consideration and reflection from the designer, as in this view designers “[do] not have a choice of referencing or not referencing beliefs; the choice lies in what beliefs are referenced” (ibid., p.48). HCI Design researchers Jodi Forlizzi and Cherie Lebbon have argued that using a rhetorical approach to Communication Design supports effective design for a diverse, pluralistic society by:

“allow[ing] designers and viewers to actively co-construct meaning through the visual message, resulting in new interactions between designer, viewer, and message. [...] Effective rhetorical communication allows individuals to relate to each other, provid[ing] a vehicle for expression, freedom, and the discovery of truth, and ultimately creat[ing] the possibility for social agreement within a pluralistic society” (Forlizzi & Lebbon, 2002, p.53).

By understanding and co-creating meaning with audiences, designers are then able to establish a shared language to effectively communicate with through designed artefacts. In this way, the designed artefacts affect a viewer’s beliefs through the arguments presented by their designed form.

2.3.6.1 Comparable Approaches within HCI Discourse

A rhetorical view of Communication Design strongly resonates with several HCI discourses. The co-creation of meaning facilitated by

interactions with artefacts links a rhetorical view to phenomenological theory, made sense of in 'Third Wave' HCI that focuses on lived, felt experience in relation to user experience (McCarthy & Wright, 2004). Within their foundational work, McCarthy and Wright demonstrated the potential for user interactions with digital technologies to be considered as aesthetic experiences—unique moments created by doing a particular activity within a particular context (ibid.). Consideration of “[the] contextual, durational, and meaningful interaction among people” has also been explored within critical HCI through Shaowen Bardzell’s introduction of Judith Butler’s feminist theory of performativity within HCI discourse (S. Bardzell, 2010, p. 31). These two approaches have since been entwined and methodologically extended for HCI Design praxes by Jocelyn Spence, through her introduction of Performative Experience Design (PED) methodology. Self-located at the far end of Third Wave HCI, Spence’s PED methodology draws from both performance studies and performativity to create a framework for both understanding and designing performative experiences with digital technologies (Spence, 2016).

A rhetorical approach to Communication Design praxis on socio-political topics such as HIV shares several similarities with Spence’s PED methodology. These include the position that “[design praxis] foreground[s] the ethical positioning of designers by revealing the intra- and interpersonal costs of interacting with technology and exposing potential harms to the public” (ibid., p. 12); and a pragmatist view that art and life are irrevocably intertwined, resonant with the concept of emancipatory responsibility for Design⁵⁰. Communication Design praxis also holds shared consideration for

⁵⁰ This is in following Jeffery and Shaowen Bardzell’s critique (J. Bardzell & Bardzell, 2013) of Dunne and Raby’s initial positioning of Critical Art as separate from Design (Dunne & Raby, 2001) because “art is too far from everyday experience to be taken seriously by most people” (Spence, 2016, p. 13).

designing moments of performativity, such as in the case of graphic designers working with a children's hospital to design better materials to support informed consent during moments of high-stress (Throop, 2006).

I find resonance with tensions inherent to the quiet reframing of the 'user' of digital technology as an 'audience' within PED. As presented by Design scholar Paul J. Nini (2006):

“The terms 'audience' and 'user' are used to denote two slightly different meanings; audiences are generally considered to be larger groups of viewers, and the research methods discussed in regard to audience-centred projects are mostly perceptual in nature (such as measuring impressions of trademark concepts); on the other hand, users are often considered to be smaller groups of viewers, and the research methods discussed in regard to user-centred projects are mostly performance-based (such as measuring a user's ability to locate a destination via viewing existing signage in an environment)” (Nini, 2006, p.118).

While strict definitions of 'audience' may differ between discourses, the general research focus on viewer *perception* as opposed to *performance* is shared by a rhetorical view of Communication Design—the immediate goal of this view of Design being to change beliefs (perceptions) rather than elicit immediate response (performance) *per se*⁵¹.

My design praxis differs from Spence's PED however in central focus and materiality, resulting from our respective creative practices: while

⁵¹ Discourse on the ability of Communication Design to effect change in relation to health outcomes specifically has recently been explored within the design exhibit (and subsequent publication) 'Can Graphic Design Save Your Life?' by design studio GraphicDesign& (Schrauwen et al., 2017). While the exhibit provides no explicit answer, the work clearly presents the impactful and significant relationship between Communication Design and Health.

PED looks to the role and design of *experiences* (the material of performance design), communication design looks to the role and design of *communication*. PED methodology focuses on the *enacted and durational* performativity of an interaction, while communication design practice instead designs for interactions that exist autonomously through designed artefacts. In other words, while PED may focus on the aesthetic experience of a woman living with HIV digitally interacting with a peer group, Communication Design focuses on the role of the digital intervention itself (its design and processes) as a means to support that experience. These different but compatible design materials mean that while PED is a methodologically complementary approach to a rhetorical view of Communication Design, it is focused on a different aspect of digital interaction because of its design material.

Because of this distinction, I will discuss comparable design praxes within HCI discourse, demonstrating how similar approaches have co-created understanding with users to inform the designed form of artefacts.

2.3.6.2 Comparable Design Praxes within HCI Discourse

To facilitate a rhetorical dialogue, a communication designer must understand the beliefs of their audience. Forlizzi and Lebbon offer that user-centred, interdisciplinary methodologies have been useful in this pursuit, however they also discuss current limitations of actually conducting user-centred research within professional design practice due to time, cost, and access restrictions (Forlizzi & Lebbon, 2002). As discussed previously, there has been critique from Critical Disability Studies scholars within HCI on the use of empathy as isolated and/or 'checkbox' stage within design processes (C. L. Bennett & Rosner, 2019), which may be related to similar costs within research. However, in taking a craft perspective of Design-led

Emancipatory HCI empathetic design activity is recast as ongoing, unfolding, and integral to design praxis itself, making it impossible to isolate (and thus limit or 'optimise').

Within HCI discourse similar empathy-led craft perspectives for Design have been shown through the respective work of designers Jayne Wallace and Leah Heiss.

Jayne Wallace has engaged with an empathetic process of making within her own design praxis, engaging in dialogue with her participants, then with the materials she uses to respond to those dialogues, over and over in an ongoing and unfolding dialogue⁵². Her Design-led inquiry “use[s] the process of designing and making... not to present solutions emerging from our analysis, but to help us structure our inquiry... to frame the questions to which we sought answers in ways which were valuable, meaningful and interpretable both by us and [our participants]” (Wallace et al., 2013, p. 2625). In this way Wallace has used an empathic design praxis to co-create a shared language with her participants through her design praxis; placing equal importance on *what* is made and *how* it is made.

A similar approach and use of empathetic engagement can be seen in designer Leah Heiss's work, however she has expanded this approach to include consideration for both trans-disciplinary teams and final users of her wearable design works (Heiss, 2019). Heiss frames these empathetic activities within her design practice as 'relationship building': “fleshing out the relationships between people and artefacts; and between people and other people” (ibid., p. 98). Heiss's practice also includes consideration for what she refers to as

⁵² Because of this her design praxis has been described as “a process of learning and responding rather than a process of representing” (Wright & McCarthy, 2008, p. 641).

"material empathy", or the tacit expertise needed to work with design materials and processes.

When viewed through the lens of craft-led Emancipatory Design, the emergent artefacts of both Wallace and Heiss's design practices push towards the possible futures of their user collaborators in emancipatory ways. Both designers use their position as Design expert (with 'material empathy') to work in coalition with participants, the voiced expertise of collaborators informing and guiding their craft throughout the design process. Through their mutual involvement in jewellery making as craft, the design of artefacts as 'precious' things goes beyond materiality to also consider personal meanings attached by the user to the artefact: "the maker interpreting and reflecting personal significances in the form and function of the artifacts (sic)" (Wright et al., 2008, p. 19). The socio-material entwinement between user meaning and artefact materiality repositions design outputs as emergent from the co-created language formed between designer and collaborator, offering the means in which to co-create design outputs that pursue preferred future(s) through their creation and existence. This entwinement holds functional and aesthetic values as *equally* important to the emergent artefact. This challenges the arguably normative approach within broader HCI discourse that places function (which can be optimised) ahead of aesthetics (which is subjective), instead viewing them as entangled aspects key of any successful design output. Heiss has notably used this entanglement to pursue emancipatory design works in relation to the socio-materiality of disability, shifting the focus from disability to desirability when working within industry to create new assistive technologies (Heiss, 2019).

While Wallace and Heiss's craft perspectives are largely in relation to physical products (such as wearables), I have been informed and

inspired by their design praxes and apply a rhetorical view of Communication Design within my developing thesis. Their respective works present a foundation from which Emancipatory Design praxes may build upon: by taking a craft perspective in which empathy is ongoing and unfolding, through which both process and artefact are equally important, and in which function and aesthetics are entwined. However, whilst both design praxes are arguably emancipatory, and Heiss's work involving disability challenges stigmatising notions of 'abnormality' through Design, neither practitioner explicitly engages with their practice as socio-political action. I aim to extend empathetic craft-perspectives within HCI Design by explicitly incorporating emancipatory intent. In other words, I seek to actively engage with how the socio-materiality of crafted artefacts challenge stigmatising beliefs about HIV and those who live with it. I now turn to offer examples of this approach within academic and activist Communication Design practices involving HIV.

2.3.7 Emancipatory HIV Communication Design

HCI design scholars Jodi Forlizzi and Cherie Lebbon establish that a rhetorical approach to Communication Design requires designers to think beyond what they make; considering not only how communication is facilitated by designed artefacts, but also how that communication then affects the beliefs of the viewer. As a rhetorical approach to Design creates new beliefs by referencing existing ones, Forlizzi and Lebbon establish that designers must be aware and considerate of how designed outputs interact with viewers:

“Designers can no longer only be concerned with the interaction of word and image; they must also be concerned with the interaction between the audience, the content of the communication, and the outcome of the design” (Forlizzi & Lebbon, 2002, p. 54).

This means that designers must consider how the interaction between artefact and viewer affects a viewer's beliefs as design outcome⁵³. In the context of HIV, this includes consideration for the emancipatory effect of designed artefacts.

Within academic Communication Design discourse, HIV-related design works have generally included aspects of a rhetorical view of Communication Design, CBPD, and Emancipatory Design: empathetically engaging with collaborators to create meaningful outputs, adapting the role of the designer (and design processes) in relation to the unfolding collaboration, and maintaining emancipatory intent for both design processes and outputs in coalition with collaborators. Examples include Audrey Bennett *et al.*'s participatory design of HIV/AIDS awareness and prevention posters in Kenya (A. Bennett et al., 2006), which used co-design processes to generate aesthetically appropriate health promotion posters while facilitating graphic design training; and Matthew Wizinsky's public health and history work with women living with HIV in the United States (Wizinsky, 2019), in which he entwined "basic research, applied interdisciplinary research, and community-engaged advocacy" within his praxis to illuminate structural barriers to health by uplifting personal experiences of those barriers (*ibid.*, p.4). Interdisciplinary work involving Communication Design has taken similar approaches, such as Criminology scholar and HIV activist Alexander McClelland's collaboration with illustrator Eric Koustik Williams and design agency Mixtape Branding to create a zine⁵⁴ on the experiences of those criminally charged, prosecuted, or threatened with charges because they had allegedly not told sexual partners of their HIV status in

⁵³ I interpret 'the outcome of the design' to refer to the affectual change in beliefs that a rhetorical view of design aspires to cause, i.e. what happens when the audience/user interacts with the design output.

⁵⁴ A zine is a self-published publication, usually created and distributed by the same individual(s) or group(s).

Canada (McClelland, 2019). Within these examples, design processes and resulting artefacts engage with the socio-political context of HIV and challenge negative conceptualisations of what HIV (and living with HIV) means.

Consideration of the socio-materiality of HIV can also be seen within modern community-led HIV activism through art, including works that are digitally mediated. Examples include the work of Mel Rattue, an UK-based artist and activist who founded the '#PositiveAffirmationDay' movement on Instagram and Facebook within her 'PositivelyMindfulHIV' platforms (Cricketlv, 2017)⁵⁵.

Another example can be found in the ongoing 'PosterVirus' initiative, led by the AIDS ACTION NOW! advocacy group in Toronto, Canada and collaboratively developed by artists and academics Alexander McClelland and Jessica Whitbread (McClelland & Whitbread, 2016). The PosterVirus initiative has collaborated with a range of artists, each creating a poster to challenge the limits of how HIV/AIDS can be discussed within society⁵⁶. Collaborative, community-based

⁵⁵ What began as Rattue drawing pictures of people living with HIV along with three words important to the person (beginning with the letters H, I, and V) in December 2014 quickly grew with international demand, soon requiring that pictures submitted by individuals be used rather than drawn portraits.

⁵⁶ Within their 2012 collective statement, PosterVirus clearly articulates the contextual need for continual development of communication design on HIV/AIDS:

"We are tired of individualized responses that ignore the realities and complexities of our lives. We are tired of being defined through acronyms. We are tired of the buzzwords, language that privileges groups over others and the increased divide between us and them. The bureaucratization of AIDS that has silenced and marginalized voices that complicate for too long. With this project we are calling for a return to dialogue and complexity. We are moving away from one-way social marketing AIDS campaigns. We are critiquing Public Health messages that individuate people and divorces them from the harmful impacts of institutions and the state. This is why these works were developed as a dialogue between activists and artists, and this is why we encourage these works to help promote community dialogues. We continue the tradition of claiming space for those of us who are most impacted by the epidemic. We hope that these works provoke, critique and encourage new ways of conceptualizing and talking about AIDS. The AIDS experience is spoken through many voices. As a diverse community, we have always been able to take care of each other. We need to remember where we came from. We need to continue to self-organize" (McClelland, 2012).

design work, when used as an extension of self-organising, has established itself as a means not only of expression and identity construction within HIV/AIDS communities, but also of survival and space-making within society⁵⁷. Within HCI discourse, this kind of political argumentation enacted through designed artefacts is closely connected to Adversarial Design.

2.3.8 Adversarial Design

A rhetorical view of Communication Design can be considered within the scope of Adversarial Design. HCI designer Carl DiSalvo defines Adversarial Design as a theoretical construct which, “through designerly means and forms... evokes and engages political issues” through agonism (DiSalvo, 2015, p. 2)⁵⁸. Rather than viewing the plurality of beliefs within disagreement as something to be reduced (e.g. by reaching an agreement), agonism is viewed as a condition of everyday life—focusing on the ‘political’ as “a condition of ongoing contest between forces or ideals,” as opposed to ‘politics’ or “structures and mechanisms that enable governing” as the focus of engagement (ibid., p.8). In this way Adversarial Design is political design, not the design of politics, and operates as a theoretical construct (“a tool to think and make with” (ibid., p.17)) rather than a design movement.

This statement strongly connects with the aims of an emancipatory, CBPD, and rhetorically informed design praxis: using the designed artefact (posters) and their making process as means to facilitate a political dialogue not just between activists and artists but also within larger community groups.

⁵⁷ This statement also calls out the harms of Communication Design when used without awareness or care of its political context, such as through the ‘bureaucratization of AIDS’ and ‘Public Health messages that individuate people and divorces them from the harmful impacts of institutions and the state’.

⁵⁸ The political concept of agonism “emphasi[s]es the affective aspects of political relations, accept[ing] that disagreement and confrontation are forever ongoing” (DiSalvo, 2015, p. 5).

Designing digital interventions for HIV peer support as a form of Adversarial Design positions health and social support provision for people living with HIV as a political act, a novel approach in Digital Health research. This is an uncomfortable premise to consider, however it is one that has continued to appear within the reality of HIV service provision in the UK to this day; women living with HIV continue to report experiences of discrimination, violence, and abuse within healthcare settings (Auzenberg et al., 2018; Sophia Forum & Terrence Higgins Trust, 2018).

Adversarial Design offers a pragmatic means for design praxes to approach this rhetorical complexity. Building on John Dewey's understanding of inquiry as a means of providing clarity to enable action, DiSalvo defines inquiry within Adversarial Design as "a process of skilled examination and reconstruction that renders problematic situations sense-able" (DiSalvo, 2015, p. 116). Through this definition DiSalvo positions Adversarial Design praxis as both (1) competent of thought and action ('skilled') and (2) "[giving] form to problematic situations... a coherent object or event that has a perceivable structure and significance" ('sense-able') (ibid. p.116). In other words, the designer must understand the political dialogue at hand, figure out how to design in consideration of that agonism, and then be able to make a design outcome (e.g. an artefact) from that understanding. This echoes a rhetorical view of Communication Design, in which a designer must understand beliefs of their audience(s) and translate them into a material form to argue for new beliefs within the viewer.

Adversarial Design outcomes serve as "believable models for future actions and conditions"—examples of what could be through agonism of what currently is (DiSalvo, 2015, p. 119). While within Adversarial Design discourse this is often pursued through critical or

speculative design approaches (including for women's health (J. Bardzell et al., 2019)), DiSalvo notes that Adversarial Design is not limited to these practices alone. This approach has further informed how I position my doctoral work within the HCI field, aligning with a *participatory* Adversarial Design praxis.

2.3.8.1 Participatory Adversarial Design & HIV

In concluding his thesis on 'Adversarial Design', DiSalvo offers several imagined futures for what a *participatory* Adversarial Design praxis could look like, one of which being the development of "a new aesthetic that engaged speculation but without being spectacular" (DiSalvo, 2015, p. 125). I argue that this is already at work within existing participatory Communication Design praxes involving HIV, and notably through work involving women living with HIV specifically. Within these extant praxes, designers work in coalition with women living with HIV to co-create a shared language of beliefs, using this understanding to inform the design of artefacts, which in turn promote emancipatory changes in stigmatising beliefs about HIV (and what it means to live with it).

One such example is Education and Women's Studies professor Patti Lather and feminist psychologist Chris Smithies's research and subsequent book, 'Troubling the Angels'. Within their book Lather and Smithies weave transcripts of their interviews with women living with HIV and AIDS attending support groups in early 1990s Ohio with author notes and conversations, letters (sent and unsent), statistic information, and angelology⁵⁹ to curate an experimental ethnography

⁵⁹ Additionally, the authors chose to use angels as a means to reinterpret the traditional inclusion of researcher's interpretation of a study, moving away from them stating "what the women's words 'really meant'" for the reader to instead present how the "sociological and historical layers of the AIDS" connected to the transcripts in a way that challenged readers to consider the socio-political connections themselves without spectacle (P. Lather & Smithies, 1997, p. 50).

(P. A. Lather, 1995). Their work is presented through unique layout designs by publisher Letra Libre, who assembled the book using: (1) text boxes with statistical information and excerpts of poetry and prose within the main body text; (2) angel intertexts (chapters in between transcript-based chapters) to provide additional information and to work as a troubling representation of the researcher's interpretation of the preceding transcripts; and (3) maintaining dual conversations within one page through the use of a horizontal page divide, wherein two narratives can be read separately along the top and bottom halves of the page. Through these agonistic design choices Lather and Smithies aspired to chronicle the plurality of experiences voiced by their participants without reducing them to any singular 'truth', challenging understanding of what living with HIV meant at the time.

As a work of Adversarial Design, 'Troubling the Angels' doesn't neatly fit the definition of a work using a critical or speculative approach. While its interior layout design and content uses Feminist Theory to trouble the idea of how HIV narratives are presented in text, it does not do so using speculation. The design output (a book) is widely distributed publicly, and so isn't imagining or performing potential futures within a performative agonistic context (e.g., an exhibit) but instead actively supporting reflection and debate within the reader without drawing attention to itself; it's just a book about the experiences of women living with HIV. It takes this normative (rather than speculative) stance for a specifically critical reason: to interrupt 'easy empathy' and instead challenge a reader's beliefs about women living with HIV. This unique approach to adversarial design is *purposefully designed* for the context of stigma, as by facilitating this agonism within 'normalcy' it avoids presenting political/ stigmatised topics as a spectacle or otherwise 'othering' the experiences presented; interrupting existing beliefs by refusing to

repeat stigmatising narratives, while also supporting a debate of beliefs within the reader rather than on the page. It doesn't rhetorically challenge the normal but the normative.

This normative approach has also informed recent communication designers co-creating health intervention resources with women living with HIV. Canadian design agency And Also Too co-created an infant feeding resource with mothers living with HIV, using their co-design process to inform an emancipatory output that reframed difficult conversations about infant feeding that could speak to *any* relevant audience, not only mothers living with HIV (And Also Too, 2015). By taking an emancipatory and empathetic approach to this socio-political context in coalition with collaborators (mothers living with HIV), the resulting design work again pushes towards possible emancipatory futures (a speculative impulse) without being spectacular—it operates as any health resource is meant to, therefore challenging normative beliefs that information about infant feeding options is an abnormal thing.

This 'new aesthetic' predicted by DiSalvo (2015) in relation to Participatory Adversarial Design shown through these examples echoes the findings of designers working in context of disability, presented previously in this chapter (see 2.3.5.1). Similar to the work of Graham Pullin, these works do not seek to render interventions invisible (as imperceivable or hidden) but instead, with emancipatory intent, present them as *normative*; challenging stigmatisation through the very existence of the design output itself as an unspectacular counter narrative. In reference to this, authors Elizabeth DePoy and Stephen Gilson combined Pullin's approach with Naoto Fukusawa and Jasper Morrison's contemporary design trend of 'supernormal'

(Fukasawa & Morrison, 2007)⁶⁰, undesigning the concept of ‘normal’ from a purely theoretical or statistical concept and instead locating it within Design and object worlds—as a component inherent to the form, function, and aesthetics of designed outputs (DePoy & Gilson, 2014). DePoy and Gilson then go further, arguing that when “the atypical becomes the typical when difference trumps sameness as the ‘norm’”—presenting alternative iconography for accessibility signage that presents which designed things are available rather than merely symbolising the limitation itself (e.g., showing a symbol and text for ‘braille’ rather than a symbol of an eye with a slash, symbolising blindness) (ibid., p.223). Designers working in the context of disability offer additional emancipatory examples of how agonism of the ‘normal’ has been practiced through crafting design artefacts and processes; challenging normative and stigmatising beliefs by redesigning difference as unspectacular. These designs push towards preferred futures by making them an everyday, existing, and mundane reality.

This subtle, normative use of agonism resonates with the ‘us the strange’ approach to research of sociologist Spencer Cahill (2.3.4). The previous examples focus on challenging existing beliefs within the viewer not by explicating the critical analysis of difference as the central focus of their outputs, but instead choosing to focus on that difference as all things are different. This normative approach echoes the call for asset and strength-focused research within CBPD discourse, focusing on effectual change that celebrates the unique strengths of communities. These examples all produced design artefacts that served meaningful purpose for all collaborators, in line

⁶⁰ Super Normal (or supernormal) is a paradoxical contemporary design trend that highlights the absence (and thus presence) of remarkability. As summarised by DePoy and Gilson, “Everyday objects such as stools and trash cans with unique but miniscule creativity are offered as exemplars of the supernormal, revamping the term normal and it’s superior as imperceptible and attainable exceptionality fitting within daily use and lives” (DePoy & Gilson, 2014, p. 224).

with the responsibilities of Design work considered within Fourth Wave (Frauenberger, 2019) CBPD, and Design-led Emancipatory HCI discourses (2.2.2). Lastly, these works are not Critical or Speculative Design, but none the less facilitate agonistic dialogue and serve emancipatory purpose. All are informed through participatory research, with designers working in dialogue and coalition with their respective collaborators to co-create a shared language of beliefs that informs how the form of emergent artefacts is crafted.

In reflecting on these design works, I shed light on how these examples entwine considerations of a rhetorical view of Communication Design, CBPD, craft perspectives on Design-led Emancipatory HCI, and Adversarial Design within their praxes and emergent artefacts. These design praxes create artefacts that challenge stigmatising beliefs about HIV through subtle antagonism of what is normative, pushing towards emancipatory futures in coalition with their collaborators. At the same time, these artefacts also serve pragmatic purpose, creating the things that communities wish to see in the world by drawing on their strengths, assets, and beliefs to inform the design processes and outputs of these collaborative works. These combined considerations inform an approach to design praxis that is uniquely suited to design work within stigmatised health contexts; *a novel approach that informs my work within this this doctoral project*. My approach draws on emancipatory community-based design praxes, rhetorical and Adversarial Design praxes, and empathic design praxes to position designers as collaborators, working together with communities to co-create meaningful artefacts that serve pragmatic purpose; artefacts that also argue against stigmatising beliefs within the viewer through their designed form (summarised in Fig. 3 below).

KEY THEORIES & CONCEPTS MAP

LEGEND (KEY RESEARCH AREAS)

Disability Studies

Participatory Design (PD) and Community-based PD (CBPD)

—○— Established connection

—●— Novel connection

DESIGN CONTEXT (2.1)

Exploring the social needs and concerns of women living with HIV in the UK in relation to the design of digital social support interventions

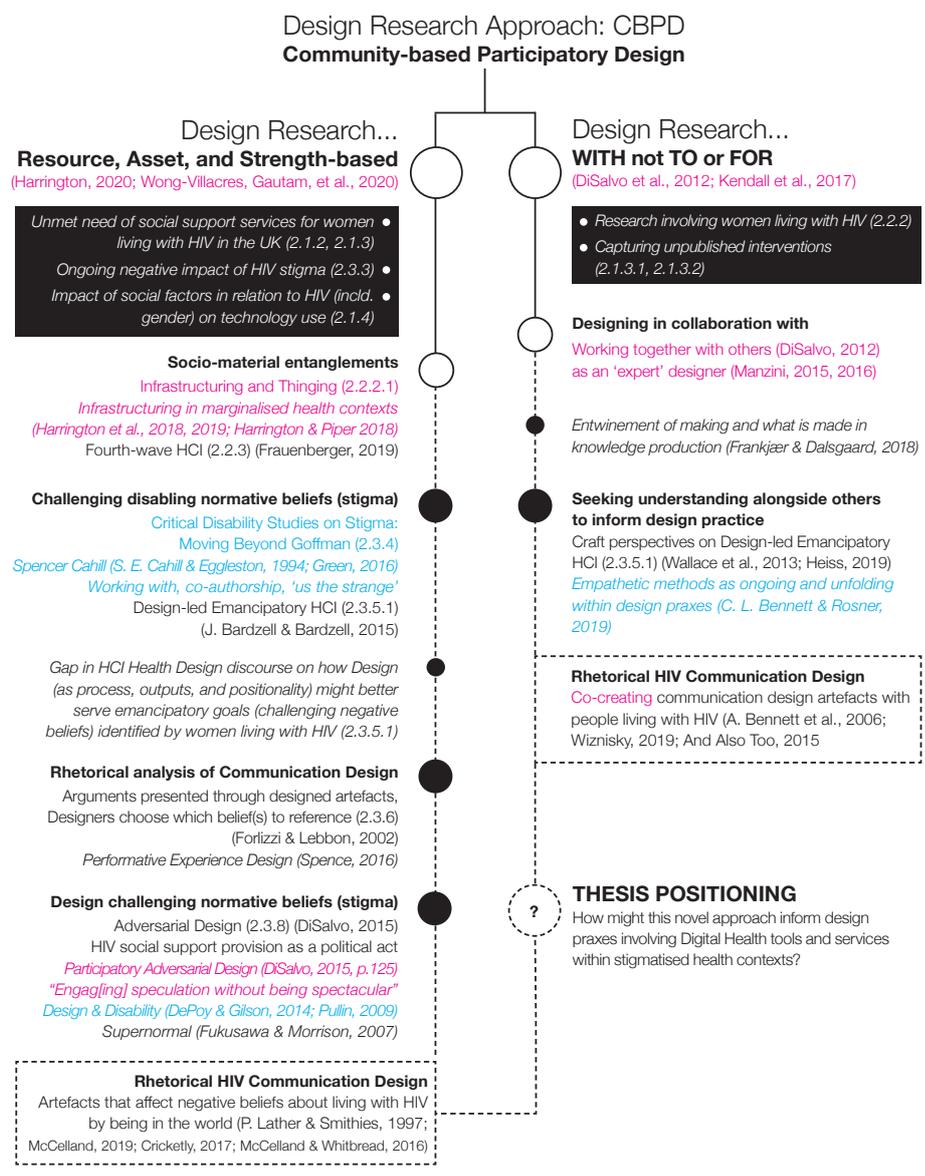


Figure 3: Key Theories & Concepts Map highlighting the key theories used in my novel design research approach and their connection to academic work in several academic disciplines. Connections to PD/CBPD and Disability Studies have been specifically highlighted to note the entwinement across both key concepts of my CBPD approach. Image by Author.

I position this thesis within this space, exploring how the novel approach that I have outlined within my Contextual Review may inform design praxes involving Digital Health tools and services within stigmatised health contexts. I use a craft-led approach to CBPD to bridge the gap between Design-led Emancipatory HCI (seeking the enactment of preferred futures) and the critical and speculative approaches of Adversarial Design (which seeks to explicate critical issues and speculate about potential futures). Whilst these examples of Participatory Adversarial Design involving women living with HIV shed light on how the design process and emergent artefacts of this approach may unfold, this doctoral work represents the first time this approach has been used within the HCI field for the co-design of artefacts. I expand further on this methodological approach in the next chapter, in order to clarify my approach for the benefit of other designer-researchers working within stigmatised health contexts.

2.4 In Summary

In this chapter I presented a Contextual Review of the research landscape of this doctoral project, considering digital social support interventions for women living with HIV in the UK, and highlighting the unmet needs, decreased funding, and intersectional marginalisation within this group. Building on this contextual understanding, I have outlined the methodological orientations of my developing thesis: I highlighted and critically reflected on the tensions between Community-Based Participatory Design (CBPD) praxis and traditional research practices; and I noted the similarities between CBPD and other PD praxes. I then positioned CBPD within the incoming Fourth Wave, 'Entanglement HCI' (Frauenberger, 2019) paradigm.

After establishing the potential value of this conceptual framing, I considered how the ethical responsibility of Design within stigmatised health contexts could be enacted through design research praxes and its emergent artefacts. I first synthesised insights on stigma from Critical Disabilities Studies, HIV, and Design-led Emancipatory HCI discourses, using this to highlight a gap in HCI Health Design discourse for which a rhetorical view of Communication Design is well-positioned to respond to. I compared and contrasted this novel design praxis to existing approaches and design praxes in HCI discourse, highlighting its unique contributions. I then introduced specific examples of this design praxis within Communication Design work involving HIV to shed light on the inherent political and socio-material considerations of this approach. From here I positioned this novel approach to HCI Health Design within Adversarial Design discourse, further defining it within Participatory Adversarial Design. I then outlined this novel design approach, developed further within the next chapter and utilised within the proceeding doctoral works.

I now turn to introduce my novel, theoretically grounded extension to CBPD methodology, informed by the perspectives engaged through the contextual review. In Chapter 3, I also provide an overview of the specific methods I employed in my empirical studies, which I report on in more detail within Chapters 4-7.

3 Methodology

3.1 Introduction

In the previous chapter I synthesised a number of theoretical perspectives from related work and positioned my research aims and motivations in relation to existing discourses (2.2-2.3). The review informed my approach to design research and praxis within the complex context of HIV, outlining the need for methodological expansion involving the co-creation of design artefacts. In this chapter I first define how this methodological extension informs ‘appropriate’ approaches to emancipatory co-design work within stigmatised contexts (3.1.1). I then provide an overview of my novel extension for CBPD methodology, Community-Based Co-Design Praxis (3.2), highlighting connections with existing Design discourses and praxes, and adding further theoretical depth. I then briefly summarise my justification for devising this approach, and highlight its distinction from similar discourses (3.3). Lastly, I give an overview of how this methodological approach has shaped my complementary qualitative studies (3.4).

My studies have focused on understanding the conceptualisation, use, and design of digital technologies within HIV social support provision for women living with HIV, in order to inform responsible, sustainable, and emancipatory innovation. Taking a community-based approach has meant pursuing outcomes that are best suited to the unique context of each case; therefore, study methods and outcomes were developed in response to each situation. Straddling both Community-Based Participatory Research (CBPR)⁶¹ and Design

⁶¹ Where outcomes include academic posters or papers meant to influence discourse and/or policy (Coughlin et al., 2017).

(CBPD)⁶² requires methodological breadth in order to serve dual purposes equitably, as both approaches are largely informed (and given form) by the contexts in which they are applied. Because of this, I offer my novel extension to CBPD methodology as a series of pillars that may be shared across both processes, framing ‘appropriate’ approaches for ‘expert’ designer-researchers. To clarify, this chapter does not intend to propose Community-Based Co-Design Praxis as a novel methodology, but rather as a theoretically grounded extension to CBPD methodology to inform designer-researchers using design praxes within stigmatised contexts.

3.1.1 Creating shared understanding in Co-Creative Design praxes

My methodological extension to CBPD builds on the approaches outlined within my Contextual Review (2.2-2.3): pursuing possible futures by co-creating emancipatory worlds with communities. Whilst these perspectives provide much to inform the *process* of co-creation, they offer limited methodological insight into how that process might operate in the space of co-designing with politicised beliefs: how to co-design a shared language to inform design outputs. For this, there needs to be explicit understanding as to how that shared language is empathetically co-created within design praxes.

Within HCI Design and PD discourses⁶³, the choosing of an ‘appropriate’ approach for practicing collaborative design has largely been described in relation to Design Research or Making processes, rather than how these processes inform emergent artefacts.

⁶² Where outcomes include artefacts and insight into design processes meant to inform or support service delivery.

⁶³ I refer to Participatory Design discourses which position an ‘expert’ designer as equal collaborator within unfolding co-creation practices specifically.

Choosing what is ‘appropriate’ guides how designers will facilitate the co-creation of shared understanding with their collaborators, which in turn informs the material form of the subsequent designed artefact(s). The means of co-creating this shared language are often referred to as ‘empathetic methods’; these methods have been introduced (Wright & McCarthy, 2008), critically expanded upon (Bennett & Rosner, 2019), and explicitly used within design praxes involving digital artefacts (Heiss, 2019; Wallace et al., 2013) within the HCI field. Manzini describes this kind of unfolding approach as a dialogic process within PD discourse, in which “involved actors are willing and able to establish a *dialogic cooperation*—a conversation in which listening is as important as speaking” (Manzini, 2016, p. 58). In order to adopt such a dialogic approach Manzini posits that “design experts must learn to listen, but they must also learn to propose their own ideas and visions. And to do it in the most appropriate way” (ibid.); The task of choosing an ‘appropriate’ way to engage within a collaborative process is given to the designer.

These works all provide guidance on how empathetic methods are used within an unfolding collaborative process of Making. However, they offer limited guidance to inform how the designer *as an individual* makes their choices within that collaborative process; and how this in turn informs their contribution of an ‘expert’ design practice towards the design of final artefacts (Bowen et al., 2016). When pursuing emancipatory work within a marginalised context this consideration is key, as the ultimate goal of effectual change is paramount; without some form of anchoring there is always the potential for what is ‘appropriate’ to change, or become appropriation⁶⁴, should the designer only consider coalition work

⁶⁴ ‘Appropriate’ as an adjective meaning “especially suitable or compatible” but as a verb “to take exclusive possession of... to take or make use of without authority or right” (Merriam-Webster, 2021); the appropriation of empathetic and

through the process of research activities. This issue is at the core of community-based approaches, which require outputs to be provided as guided through a collaborative process. Mutual concern for both design process and emergent artefact takes on additional weight within the context of a politically engaged Communication Design praxes, as emergent artefacts utilise beliefs in order to affect a viewer's understanding. These beliefs may differ between collaborators, affected by each person's unique experience of being in the world, creating the potential risk for stigmatising beliefs to be materially translated through a designer's involvement.

As I myself do not presently live with HIV, using a rhetorical (2.3.6) co-design process means that my perspective is held in dialogue with women who do, and/or those who provide services for them, to co-create a shared 'language'. As HIV has historically been politicised, and stigma is a socially informed belief, I likely hold different conceptualisations of what it means to live with HIV than those who I have worked with. How might I best support an emancipatory praxis if my own insight and input within a collaborative process might unintentionally reproduce forms of bondage or trauma, whether through process or product? Existing literature on 'appropriate' processes arguably does not adequately respond to this issue in relation to co-creation, as it is largely a matter independent of the process itself. This issue is instead located within the designer, as an individual in a collaborative encounter, and their expert use of 'material empathy' (Heiss, 2019)—their design praxis of translating understanding through designed forms.

In order to address this gap in the literature I offer my novel theoretical expansion for CBPD methodology. I contribute this not

participatory design methods in HCI discourse being discussed within Bennett and Rosner (Bennett & Rosner, 2019) and Manzini's (2016) works respectively.

only to benefit Emancipatory HCI research agendas (Bardzell & Bardzell, 2015), but to also support clarity about the contribution of Design Studies within the interdisciplinary HIV field. Easing methodological translation between disciplines is ethically important within the context of my work given the reliance of HIV support services on non-Design funding bodies to operate. I anchor my extension with additional theoretical influences to explicate an ‘appropriate’ conceptual foundation for configuring a ‘expert’ design praxis that may resist appropriative (Bennett & Rosner, 2019) applications within CBPD research.

3.2 Community-Based Co-Design Praxis

As this doctoral work is concerned with understanding the lived experiences of women living with HIV in order to inform emancipatory digital innovation, I have drawn upon Critical Phenomenology to guide my approach. As introduced earlier (1.0), Critical Phenomenology is a contemporary phenomenological discourse that incorporates discussion on the relationship between Phenomenology and Critical Theory, (Guenther, 2020)⁶⁵. I root this philosophical ‘family tree’ in the work of two key phenomenologists, Edith Stein and Emmanuel Levinas, and critical theorist Jacques Derrida (via Simon Critchley). From this positioning I root my understanding in how empathetic methods may be critically and responsibly used within an ‘expert’ design praxis.

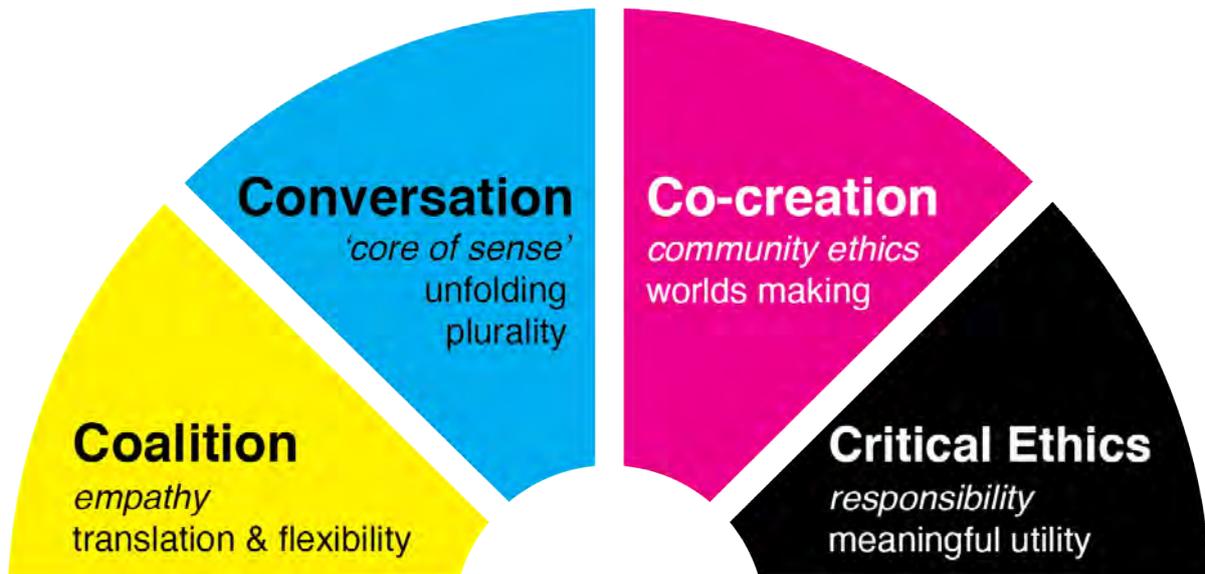
I have named my novel extension to a CBPD methodological approach Community-Based Co-Design Praxis (CBCDP) in order to position it in relation to (and distinguish it from) existing discourses:

⁶⁵ In formulating my methodological approach, I am interested in how the philosophical foundations of Phenomenology can connect to the underpinning Postmodern Theory inherent to Critical Theory. To my knowledge this connection has not been explicitly drawn within HCI or Design discourses, despite there being an established connection between the two.

framing it as a conceptual foundation for guiding an '*expert*' design praxis (or crafting, making, designing), pursued in coalition with communities. This approach bridges empathetic design praxes and CBPD in HCI, viewing the involvement of 'expert' designers within co-design processes as an opportunity for emancipatory processes and outcomes when done in coalition with marginalised collaborators.

Community-based Co-Design (CBCD) has previously been presented as a methodological approach in both Health and Decolonising Design discourses, albeit in different ways; I will briefly discuss this later in this chapter (3.3.1). My methodological extension differs through its explicit focus on design praxis, or how a designer's understanding shapes the material form of designed artefacts ('material empathy'), as done through empathetic methods within 'expert' design practices. It is a rhetorical (2.3.6) design praxis, in which empathetic methods scaffold unfolding conversations between a designer and their collaborator(s) to inform a shared language that is refined throughout the design process; design research and practice informing each other.

Within the following subsections I will describe CBCDP's four pillars (Coalition, Conversation, Co-creation, and Critical Ethics (Fig. 4); and each pillar's respective (1) theoretical foundations; (2) relationship to existing HCI discourse(s); and (3) practical manifestation(s) within design/research praxis.



Community-Based Co-Design Praxis

Figure 4: Community-based Co-Design Praxis and its four pillars (Coalition, Conversation, Co-creation, and Critical Ethics). Image by Author.

3.2.1 Coalition

To work in coalition means to work towards a shared goal together as separate individuals, unified through combined efforts. This pillar resonates with the commitment of *seeking partnerships* rather than *representing the experiences of others*, put forward within Bennett and Rosner’s critique of empathetic methods within HCI Design discourse (Bennett & Rosner, 2019). I further flesh out this commitment in relation to design praxis through Edith Stein’s⁶⁶ (1891-1942) phenomenological theory of empathy, in order to explicate how empathetic methods may build shared understanding between designers and collaborators, while not assimilating or assuming the experiences of others, within a co-design practice.

⁶⁶ The importance of an empathetic relationship between an individual and the other, and how this in turn supports the importance of communities, is central to the work of phenomenologist Edith Stein. A student of the founder of phenomenological theory, Edmund Husserl, Stein’s foundational extension of phenomenological theory focused on how empathy operates as an intentional, *embodied* interaction, distinct of other experiences directed towards the other, such as sympathy or compassion (Stanford Encyclopedia of Philosophy, 2020).

3.2.1.1 Theoretical Foundation: Edith Stein's Empathy

Stein provides a framework for understanding the process of empathy as an embodied experience (Stein, 1989). When considered as an embodied act, Stein proposed that an empathetic encounter involves a three-step process:

1. The emergence of physical signs of another's experience via expression or body language, which the viewer observes (e.g., someone crying);
2. The empathiser explicates the situation in which this expression is being caused, filling in details experientially (e.g., why I understand them to be crying, based on my experiences of crying);
3. The empathiser has then synthesised an understanding, referred to as an 'intentional object' within phenomenology (Stanford Encyclopedia of Philosophy, 2020), which can then be reflected on (e.g., I can understand them to be crying because I have experienced X).

By completing this process, an empathiser does not put themselves 'in the shoes of' another, but rather seeks to understand them from their external position: "In empathically re-enacting another's experiences, **I am 'alongside' the other' but never 'one with' her**" (Stanford Encyclopedia of Philosophy, 2020)⁶⁷. When co-creating shared understanding, the emergent 'intentional object' (one's individual understanding) may then be translated to another; this exchange informing mutual understanding.

Stein's positioning of the empathiser as being 'alongside but never one with' *deeply* resonates with both CBPR (e.g. "working **WITH**

⁶⁷ An individual (as the empathiser) may therefore embody an empathetic encounter with the other while also retaining a distinction between the self and other. One does not 'feel with' another but seek to explicate an 'intentional object' which may then be used to develop shared understanding.

each other, not doing **TO** or doing **FOR** one another” (Kendall et al., 2017, p. 29) and the call of previous work within HCI to use empathy as a means of ‘being with’ collaborators (Bennett & Rosner, 2019). In the context of design praxis, Stein’s empathy supports an empathetic attempt to ‘walk with’ others by establishing ‘intentional objects’ as the material with which to co-create shared language (e.g. understanding, visual translation, etc.) without assuming to have felt their experiences: using these ‘objects’ as the means to engage in rhetorical ‘dialogic cooperation’⁶⁸ amongst collaborators.

3.2.1.2 Coalition: Implications for Praxis

This configuration of empathy guides my design praxis in coalition with women living with HIV, designing and researching *alongside* these collaborators. This has two major implications for design praxis: translation of understandings and the form(s) of final design and research outputs.

Firstly, this pillar prompts me to be humble in my translation of understandings and discuss my ‘intentional objects’ with my collaborators throughout the research/design process. Within my research approach this manifests through study design discussions with collaborators and additional review and revision cycles for all analytic and output production⁶⁹ phases. This positioning allows me to engage with my design practice as an ‘expert’ designer, while flexibly tempering my understanding and emergent work alongside others.

Secondly, in allowing my praxis to remain flexible to unfolding understandings, the final form(s) of design and research outputs are

⁶⁸ Dialogic cooperation meaning “...a conversation in which listening is as important as speaking” (Manzini, 2016, p. 58).

⁶⁹ E.g., paper writing, creation of design artefacts, etc.

foremost shaped by the coalition between ‘expert’ designer and their collaborators. This aligns with a CBPD approach, ensuring that design/research activities serve all collaborators equitably. By positioning my design praxis alongside collaborators, we first decide what to make together, then co-create shared understanding, and then decide on the final form(s) of this shared understanding; continually reshaping emergent outcomes in response to the unfolding shared understanding. In this way both research and design process and resulting output(s) are created in coalition – an empathetic process informing both understanding and form. Stein’s conceptualisation of empathy helps guard against potentially extractive or appropriative design research practices by offering ‘intentional objects’ as a means for understanding, to be discussed, refined, and defined together.

3.2.2 Conversation

To hold a conversation is to see shared understanding as unfolding, not permanent. We converse in order to build our understanding through the responses of others, which may include multiple unique voices. In this way conversation allows for many voices to be present without merging into one, allowing for plurality and potential paradox while building shared understanding together. This pillar builds upon two of Bennett and Rosner’s (2019) commitments for designers, viewing the use of empathetic methods by HCI designers as an ongoing process of attunement (rather than achieving eternal understanding) that recognises asymmetry (rather than attempt symmetry). I build upon these commitments in relation to design praxis through Edith Stein’s theory of a community ‘core of sense’. Engaging with this theoretical perspective, I consider both (1) how *plurality* relates to the emergent co-designed outcomes of my studies, and (2) how a ‘core of sense’ operates as an *unfolding* understanding throughout the design and research processes.

3.2.2.1 Theoretical Foundations: Edith Stein's Community 'Core of Sense'

Stein proposes difference between a society, where individuals treat each other individually as *object*, and communities, where individuals encounter one another as *subjects* (Stein, 2000). While societies are formed through common goals and rational planning, Stein argued that communities were instead linked through bonds of solidarity, wherein "members are 'open' towards each other... [letting] each other's attitudes and evaluations penetrate one another and deploy their mutual influence on each other" (Stanford Encyclopedia of Philosophy, 2020).

Stein's theory of empathy, in concert with her understanding of communities as 'open' to one another's influence, supports a *plurality* of experience, in which both individual and community-held beliefs exist. Stein refuses to isolate these as entirely separate, instead focusing on how individuals affected community-based understandings and vice-versa (*ibid.*). She proposes that this is facilitated by community members dynamically maintaining a 'core of sense' as a community, which varies between individuals via 'experiential colouring' (Stein, 2000).

3.2.2.2 Conversation: Implications for Praxis

Stein's concept of a *plurality* of experience (both within communities and individuals) proposes that there is no eternally perfect way to define a community; rather there is a dynamic 'core of sense' maintained by the community itself. In relation to a design praxis using a CBPD approach, the focus of using empathetic methods becomes not to try and represent the 'truth' of a community per se, but rather to co-create meaning *with* the community in a way that facilitates a conversation about the 'core of sense' through the

design process which informs final outputs. In using this conceptual approach, the designer remains 'open' towards others within their praxis, continually conversing with collaborators to (re)frame shared understanding throughout the design process.

Stein's concept of a 'core of sense' guides my design praxis, ever-evolving (echoing symbolic interactionism) and comprising a plurality of experience rather than a singular truth. This insight informs the form of my research outputs, aiming to communicate the 'core of sense' refined by co-design and co-research activities through the collage of experiences, rather than to seek to distil a solitary representation. This is well suited to work engaging with the diversity of women living with HIV in the UK and their experiences. This has informed my use of qualitative research methods (in which a plurality of voices may be retained within a single theme or code) and collage-inspired approaches to design artefacts.

3.2.3 Co-creation

Within a collaborative design praxis, making and what is made are equally important and inform each other. Collaborators work as equal partners-in-the-world, understanding that design processes and outputs help create the worlds that we live in. Together we decide what is made (outputs) and how it is made (process) in order to create possible futures.

Through the lens of an 'expert' design practice, socio-materiality is an important aspect of the world-making facilitated through design processes and outputs, as each are afforded by its form and what it communicates. This pillar builds on empathetic design praxes within HCI (Heiss, 2019; Wallace et al., 2013) to pursue an 'expert' design practice that works collaboratively with others to shape the socio-materiality of design processes and outputs—how they communicate

beliefs through designed form. As I have conducted my studies within a political context (DiSalvo, 2015), I consider also how designers might push towards preferred futures with their collaborators through the realisation of ‘appropriate’ emancipatory processes and outputs: creating the worlds that we want by making them together. This pillar is informed by Edith Stein’s theory of community ethics, explicating the ethical importance of ongoing collaboration with others within a politically engaged co-productive design praxis.

3.2.3.1 Theoretical Foundations: Edith Stein’s Community Ethics

Stein’s positioning of empathy as an *embodied* experience positions its ethics as informed by *people*, not a process. This builds on her conceptualisation of societies (as disembodied mutual agreements or ‘the state’) treating individuals as *object* in seeking to enact shared goals compared to communities, where individuals encounter one another as *subject* building towards a ‘core of sense’ (Stein, 2000). Because of this difference she argued that ethical values are created and supported by embodied community voices, so they (people) must be included if a disembodied process is to be ethical⁷⁰: “[the] state doesn’t have any proper ethical value... values can only be attributed to their underlying communities” (ibid.)⁷¹.

⁷⁰ Stein believed that while it is possible for communal decisions to be made within societies broadly, these decisions would not necessarily be rooted in ethical values, as values emerge from communities of people rather than occurring inherently within a system.

⁷¹ It is worth noting that Stein’s academic career was greatly (negatively) impacted by the rising influence of Nazis within her home country of Germany; This influence ultimately leading to her death at the Auschwitz concentration camp in 1942 (Stanford Encyclopedia of Philosophy, 2020).

3.2.3.2 Co-creation: Implications for Praxis

Firstly, this pillar recognises the importance of socio-materiality within design practice and observes how co-productive processes may benefit through the inclusion of 'expert' designers. Design processes and outputs contribute to world building by creating (in part) the worlds we experience, and so designers may contribute their expertise toward co-creating preferred futures.

When considered in the context of design praxis, Stein's distinction of ethical values being situated within individuals, rather than in systems, challenges the idea that it is ethically appropriate for designers to only foster empathetic engagement as an early, isolated activity in a design process. Her positioning of ethical values (informed by a 'core of sense') as a continual, embodied practice instead echoes recent criticism of the contemporary use of empathetic design methods within HCI discourse (Bennett & Rosner, 2019)⁷². Stein's conceptualisation of empathy as an embodied experience provides a theoretical foundation for a *continual* empathetic engagement within a co-productive design process. In other words, empathy becomes both a design practice and a continual, embodied process of meaning-making. This positioning informs my use of a community-based methodology and my inspiration gleaned from empathetic design practices within HCI (Heiss, 2019; Wright et al., 2008), for conducting my design praxis in *coalition* alongside my collaborators.

Pragmatically, this pillar entails (1) recognising the importance of socio-materiality within co-design process and outputs; (2) ongoing conversation with collaborators at all stages of research (in line with

⁷² Stien's conceptualisation of empathy also strongly resonates with the design approach outlined within the Design Justice Network Principles (Design Justice Network, 2018) and its utilisation of the call for 'nothing about us without us' created by disability rights activists (Costanza-Chock, 2020).

a community-based approach) to be an *ethical requirement* of process and/or practice; and (3) that final outputs hold shared authorship, reflecting the collaborative ownership of knowledge and the unfolding process. By unfolding ‘expert’ research and design activities in conversation with collaborators and representing this co-creation through shared authorship of final outcomes, this pillar pursues political and emancipatory goals: acknowledging all participants as experts in their own experiences, united in coalition within a collaborative pursuit.

3.2.4 Critical Ethics

My doctoral work focuses on the experiences and service provision of a marginalised group in order to pursue possible futures through the co-creation of appropriate processes and outputs. I align this work to community-based discourse within HCI through consideration of meaningful utility, or the making of processes and/or things with meaning and value for the coalition. This pillar builds upon Jonas Löwgren and Erik Stolterman’s (2007) call for interaction designers to reflect on the ethical responsibility of their practice, methodologically rooting *ethical responsibility* as a key component of design research⁷³. Remaining focused on this within a marginalised context means not turning away from whatever I am faced with, even if it is beyond my abilities to change or challenges my beliefs. I hold myself responsible for my (in)actions in response to what I am faced with; I am responsible for what I *can* do. This pillar provides the theoretical motivation to approach this challenging aspect of community-based work, illuminating my methodological approach to collaborative work as an individual alongside others. I inform this pillar through the entwined theories of phenomenologist Emmanuel Levinas (1906-1995) and postmodern theorist Jacques Derrida

⁷³ This sense of the researcher-practitioner’s answerability when working in sensitive settings has also been reflected upon in HCI (Durrant & Kirk, 2018).

(1930-2004) to guide my sense of ethical responsibility within a politicised context.

3.2.4.1 Theoretical Foundations: Levinasian Ethics and Jacques Derrida

3.2.4.1.1 On Ethical Responsibility: Emmanuel Levinas

While Edith Stein's theories inform my praxis as an ongoing conversation with others, the phenomenological work of Emmanuel Levinas (1905-1995) substantiates consideration of 'the other' as ethically important. Levinas argued that ethics should be considered as an ontology, proposing that without a central positioning of ethics individuals risk indifference towards how actions manifest against others (Levinas, 1969)⁷⁴. As summarised by philosopher Simon Critchley, "Levinas's point is that unless our social interactions are underpinned by ethical relations to other persons, then the worst might happen, that is, the failure to acknowledge the humanity of the other" (Critchley, 2014, p. 285)⁷⁵. Levinasian positioning of a 'caring' ethics as something inherent (I care because I'm alive) rather than relational (I care because of my own experiences or relationship to you) provides an understanding of care as an ethical practice through one's *responsibility* to the other, stemming from their being-in-the-world, rather than one's autonomous *relationship* to the other⁷⁶.

⁷⁴ It is worth noting that Emmanuel Levinas was also persecuted by the Nazis, living in Europe at a similar time as Edith Stein. He spent time as a prisoner of war in a Nazi labour camp in the 1940s, and, while his wife and children were successfully hidden by nuns, his remaining immediate family in Lithuania were murdered by Nazis (Stanford Encyclopedia of Philosophy, 2019).

⁷⁵ This echoes Stein's conceptualisation of the state as being without inherent ethics through the object/subject dichotomy (3.2.3.1), connecting both theories through their inclusion of 'care' for the other as distinct components of their respective theories of empathy and ethics.

⁷⁶ The importance of 'care' has previously been explored in relation to ethics within Feminist discourse on the ethics of care. The ethics of care is a feminist moral theory and methodology that positions 'caring' as the key element of moral decision-making, contrasting this approach with the typical use of objectivity as the key component in the majority of ethical theory (Taylor, 2016). However,

Guided by Stein and Levinas's theories, I establish the importance of 'caring' for the other in relation to design praxis: caring as integral component of Design to help support *better design practice*, rather than morally 'right' Design. 'Caring' is not a practice that informs Design through additional relational understanding (e.g. I care so much so therefore I understand), but instead a practitioner's *responsibility* to try to be alongside others in order to design well⁷⁷. As a designer not currently living with HIV working within a context in which I would not likely be personally affected by changes to service provision, this insight has guided my ethical design praxis, prompting me to hold my praxis responsible for its harms and benefits, in relation to both research and design's respective process and outputs, alongside collaborators. This *criticality* has been further informed by perspectives of Emmanuel Levinas and Jacques Derrida.

3.2.4.1.2 On Ethical Criticality: Jacques Derrida via Simon Critchley

Levinasian ethics shares epistemological compatibility with Critical Theory through the work of Jacques Derrida (1930-2004), the developer of the postmodern theory of deconstruction widely used in Critical Theory discourses. In his foundational text on this connection,

while the ethics of care theory places similar importance on the responsibility towards the other in relation to recognising their humanity, it does so by building on the sentimentalist tradition of moral theory: caring as a practice inspired by memories of being cared for and idealisations of the self (Sander-Staudt, 2008). This positions 'ethics of care' as a *relational* ethics rather than an ontological one. While it is beyond the scope of this thesis to expand on a full discussion of the history and critique of the ethics of care, I note this discourse in order to clarify the distinction between its methodological approach and my own.

⁷⁷ Further linking Levinas and Stien's concepts, within Critchley's reading Levinas explains that one's ethical responsibility to the other demands acknowledgement that one can never fully understand another person, recalling Stein's concept of seeking to be alongside another, and that "an *ethical* relationship is one where I face the other person and keep my distance, for distance implies respect" (Critchley, 2014, p. 286).

'The Ethics of Deconstruction', philosopher Simon Critchley argues that Levinas's phenomenological theory of ethics informs Jacques Derrida's postmodern theory of deconstruction. Through this connection to Levinasian ethics, deconstruction becomes an ethical practice, "a calling [of deconstruction] to responsibility, to be responsible," by using a Levinasian understanding of how meaning is made (ie. critique as a means of facing the other, and thereby having responsibility to them) (Critchley, 2014, p. 1). Critchley's conceptualisation of Derrida's theory creates a bond between Levinasian ethics (to which Stein's theories of empathy and community are compatible) and the use of deconstruction within postmodern critical theories (such as Feminist Theory and Critical Disability Studies). This provides the theoretical foundation on which I braid an empathetic design praxis with a critically engaged one; viewing Community-Based Co-design as an emancipatory design praxis for HCI discourse.

As an ethical practice in relation to Levinasian ethics, Derrida's deconstruction posits that "nothing exists outside context," and that, in the forever unfolding analysis of 'what that context means in relation to the thing existing within it', we are faced with a moral consciousness: ethical responsibility to respond to what we are faced with (Critchley, 2014, p. 32). In this way, an ethical practice informed by Levinas and Derrida is one of unending meaning-making; constantly seeking understanding of the context soaked into the communicated language; being alongside the other whilst being *responsible* for our response to whatever we experience. This moves beyond Stein and Levinas' considerations of how to do design research as ethical and empathetic process and outputs, to a more *critically-engaged praxis* – prompting the designer-researcher to consider how design processes and outputs will *challenge* and seek to *change* the inequalities faced. This critical thinking is arguably

inherent to community-based approaches, as they facilitate meaningful impact by positioning researchers and/or designers in coalition with collaborators.

3.2.4.2 Critical Ethics: Implications for Praxis

While the other pillars largely relate to what happens between a designer as an individual and their collaborators within CBCDP, Critical Ethics also explicates what is produced by design and research activities. By holding a designer responsible to the Other first, before what may be most compelling to pursue within academic discourse or most exciting as a design artefact, Critical Ethics focuses design praxes on meaningful utility above all⁷⁸. Co-design is a messy and complicated practice, made only more so when designing in political and marginalised contexts. By positioning critical responsibility within the individual *and* design-research processes, I hope to develop in my thesis the theoretical basis for an ethical design praxis that may cover multiple aspects of using design praxes (Chung, 2019) within research— a guiding light through both thinking and doing, making and what is made.

This pillar additionally informs my approach to ‘meaningful utility’ within an ethical design research process. Critical responsibility means remaining aware of how my actions as an individual have the capacity to impact others. By conducting design research alongside marginalised collaborators it is ethically important that I address how the research procedure or design intervention may negatively impact them (Durrant & Kirk, 2018). This may be achieved through, for example, avoiding unintentional sharing of information afforded by the design of study information documents; considering how the use of an unusual location or timing for research activities may cause

⁷⁸ This echoes the call for interaction designers to reflexively consider the ethical responsibilities of their practice (Löwgren & Stolterman, 2007).

unnecessary cost or speculation; or simply planning procedures to be flexible in response to unfolding understanding. These considerations are informed by Levinasian ethics, guiding my view of research ethics as entwined within and throughout design research methods in response to their context. Therefore, I adapt my ethical approach to each study within this thesis work, informed by their respective context and collaborators.

3.3 Methodological Justification

As described in the previous chapter, the choice to expand upon a CBPD methodological approach for this thesis work is informed by several methodological influences, spanning Design, Critical Disability Studies, HCI, and HIV fields (2.2-2.3). This methodological extension considers the importance of socio-materiality, crucial for emancipatory innovation within the complex sociopolitical context of HIV service provision and in line with current movement towards a Fourth Wave (Frauenberger, 2019) HCI research paradigm. This novel extension also provides the theoretical foundations from which I introduce the emancipatory tradition of Communication Design practitioners standing alongside and within the HIV community to HCI discourse.

The breadth of this doctoral work is limited by the depth of involvement that a community-based methodological approach demands. Collaborative relationships demand trust and ongoing communication, which take both time and experience to establish (Clarke et al., 2021). However, as this work also represents the first research on digital tools and services for women living with HIV in the UK, its focus is largely exploratory—shedding light on lived experiences and service innovations in order to establish a knowledge base to build upon in future. As such, the ‘deep’ insight gleaned through a qualitative, community-based methodological

approach is better suited to this context than the broad but ‘shallow’ insight provided by a quantitative or survey-based approach. Additionally, conducting this initial research using a community-based approach builds on previous emancipatory work within HIV discourse and sets a precedent for HCI Design research within this space; building emancipatory momentum towards community-based research practices becoming more commonly used in all disciplines involved within HIV discourse. Using a community-based approach allows my work to move away from a researcher-led agenda, rooting this new research space in fundamentally co-created knowledge in response to community interests. This methodological positioning therefore contributes new ‘deep’ insights and supports methodological innovations within HCI HIV discourse, befitting a methodological approach that values the research process and product equally.

3.3.1 Community-Based Co-Design in Health

I will briefly establish what this methodological extension is *not*. My approach is similar to but distinct from Community-Based Co-Design, as used within medical discourses (Greenhalgh et al., 2016; Haines et al., 2019). This discourse broadly draws upon Experience-Based Co-Design (EBCD) methodology, a Design Science approach. My approach differs in three ways:

(1) Flexibility: EBCD applies a formalised design process, and therefore offers *limited flexibility* for research or design processes to change, adapt, or evolve when doing community-based work;

(2) Design Craft: EBCD does not necessarily draw on an ‘expert’ designer’s knowledge of *materiality*, *aesthetics* or *craft*,

limiting its consideration of how co-design shapes⁷⁹ the form of final outputs within design praxes;

(3) Subjectivity: EBCD stems from Design Science, which views design artefacts as tools to address identified, objective problems (Johannesson & Perjons, 2014). This approach is arguably reductive within the complex and political space of HIV service provision; Stigma is a social belief it is therefore a *subjective* phenomenon that can evade objectification. I take a critical phenomenological approach, producing artefacts as manifestations of the 'core of sense' established through an unfolding conversation between collaborators: artefacts not as solutions to complexity but steps towards possible complex futures. In this way my methodological extension shares Design Science's pursuit of changing the world through the introduction of new artefacts (ibid.), and challenges subjective beliefs *in addition* to any objective 'problems'.

3.4 Methods

I will now provide an overview of the research methods devised for the empirical studies of my project, as informed by my novel methodological extension of CBPD for 'expert' designer-researchers. I have used different, but compatible qualitative methods for each study, respecting the unique contexts and goals of each collaboration and my involvement as a designer/researcher within each collaboration. Findings from these individual studies are synthesised through a process of crystallisation (sic) (Ellingson, 2008) and my analysis of the programme of work; this is reported in the Discussion

⁷⁹ While co-design is noted as a core element of EBCD, within a review of applications of EBCD in healthcare contexts it is noted that the lack of understanding of how processes inform the final *form* of co-design outputs (as done through 'expert' design practice) is a reappearing issue. The authors suggest that service designers should be more involved in EBCD work to respond to this (Donetto et al., 2014).

Chapter (8.0), where I address my three main research questions in reference to particular studies. As outlined in the Critical Ethics pillar, ethical considerations have been included in this thesis in relation to each study procedure.

3.4.1 Community-Based Framework

As a CBPD praxis within a marginalised context, my methods have largely been informed by the pursuit of ethical engagements with participants; avoiding potential harm at all costs. This has meant situating my research in connection to HIV social support service providers, both conceptually (e.g. as research partners) and pragmatically (e.g. within existing ‘safe spaces’, such as service provider offices or online spaces). This ties in well with a community-based approach, which posits that research be carried out in coalition with community partners, from initial ideation through to final outcomes, whilst also being located within existing community environments (Coughlin et al., 2017).

CBPD approaches draw from the methodological framework of CBPR. To summarise, community-based participatory methodology is based on a five-phase framework initially coded by scholar Barbara A. Israel (2005) for community-based participatory health research. This framework involves:

1. Forming partnerships
2. Assessing community strengths and dynamics
3. Identifying priority health concerns and/or research questions
4. Designing and conducting an etiologic intervention⁸⁰ and/or policy research
5. Feeding back and interpreting research findings

⁸⁰ ‘Etiologic intervention’ refers to interventions that address the cause of a specific issue or ailment, usually related to the cause or contributing factors of disease within health research (Merriam-Webster, 2020).

My research followed these phases, with my choices as a designer-researcher being guided by the CBCDP pillars. I added a sixth phase, however, relevant to design praxis:

6. Delivering an emergent design artefact.

Service provider partnerships were formed either through my own professional network or those of my supervisory academic team members. All research methods were discussed and co-developed with representatives from the involved service providers prior to finalising study design and seeking ethical approval. Once study plans were agreed upon, formal ethical permission was submitted and granted by the departmental Ethics Committee at Northumbria University (see Appendix A). This submission was then amended at various points in order to include additional considerations brought in from new research activities. In the case of my reflective account on my work with the National AIDS Trust (which was carried out during an internship), an internal contract was also developed to formalise ownership over research and connected insights within my role, separating my academic work from my professional practice within the project (see Appendix D.1.1).

3.4.2 Sampling and Data Collection Methods

Because of the additional ethical considerations and recruitment challenges inherent in working with a marginalised population, participants for all research activities were internally recruited by partnering HIV social support service providers. All recruitment activities were delivered by these providers in order to protect client anonymity, with recruitment being guided by their insight into who might be both capable and interested in participating in research activities. I designed all supporting participant information materials (e.g. information sheets, business cards) to be discreet and

unaffiliated with HIV visual identities (e.g. a red ribbon)⁸¹ to avoid relaying information unintentionally (see Appendix B.2). Research activities were scheduled to take place during regular service provision activities (e.g. group meetings) whenever possible to allow for the use of established 'safe spaces', with activities otherwise being scheduled at the convenience of participants (e.g. weekday evenings). Participants were remunerated for their time and given money for their transport to/from the research location as appropriate to each study.

The sample sizes for each study were relatively small and non-representative (7-15 people), reflective of my qualitative methods. Whenever possible, participants were exclusively women living with HIV⁸² in order to focus on the perspectives of this under-investigated group as much as possible. Participants were generally older (e.g. aged 50 years or above) and of Black African or White British ethnicity, reflecting the demographics of HIV in women in the UK more broadly, however these were not inclusion criteria.

3.4.3 Research Methods

An overview of the qualitative methods used within my doctoral work can be found in Table 1 below.

⁸¹ Visual sensibilities were informed by a visual analysis of current and historical public health communication design works undertaken as part of my initial research activities, described in Chapter 4 (also see Appendix B.1).

⁸² Only my work with the National AIDS Trust involved participants who did not exclusively identify as women living with HIV, due to the context of the design research being conducted (i.e. designing a digital tool for any person living with HIV). All other research studies exclusively involved women living with HIV.

Table 1: Qualitative methods used within this doctoral work.

Study	Participants and Sampling	Method(s)
Blue Sky Trust (BST): Study 1	8 participants; convenience sampled from an existing women's support group	<u>Method:</u> Focus Group Interview <u>Data Collection Method:</u> Audio recording <u>Analytic Method:</u> Inductive Thematic Analysis (Braun & Clarke, 2006) ⁸³
National AIDS Trust (NAT)	This work is presented as a reflective account, not a formal research study; various smaller groups of participants (<15) were involved within several research activities, referenced within this account	<u>Method:</u> Reflective Account <u>Data Collection Method:</u> Internship experience, field notes <u>Analytic Method:</u> Reflective Design (Sengers et al., 2005)
4MNetwork (4Mnet)	7 participants (5 Mentor Mothers and 2 project management team members); recruited through an internal invitation to participate	<u>Method:</u> Semi-structured phone interviews; co-research and analysis with a peer researcher <u>Data Collection Method:</u> Audio recordings <u>Analytic Method:</u> Interpretive Phenomenological Analysis (IPA) (Smith et al., 2009)
Blue Sky Trust (BST): Study 2	9 participants; convenience sampled from an existing women's support group	<u>Method:</u> Co-Design (novel zine-making method) <u>Data Collection Method:</u> Audio recordings, zine materials, field notes <u>Analytic Method:</u> Novel visual analytic process informed by IPA (Smith et al., 2009) and Visual Anthropology (Collier, 2004)

These qualitative methods align with HCI Design Research's goal of reaching towards outcomes that are 'right' for their respective

⁸³ There have been additional publications that further updated Braun & Clarke's definition of Thematic Analysis since their foundational 2006 work (used above) (e.g., Braun & Clarke, 2012, 2019b), however I have purposefully selected to use this reference given its clear framing of Thematic Analysis as a flexible (non-homogenous) qualitative analysis method (Braun & Clarke, 2019a).

context, rather than the scientific goal of establishing outcomes that are concretely ‘true’ (Zimmerman et al., 2007). When research activities included verbal discussions⁸⁴ audio recordings were made with consent, which I transcribed and anonymised or pseudonymised (depending on respective study design) to maintain participant confidentiality⁸⁵. All physical materials used during research activities (e.g., worksheets, design materials) were designed and provided by me, with collaborator input informing their design.

In line with the fifth phase of community-based approaches introduced earlier (3.4.1), all analytic methods used include some form of co-analysis. Further detail of how this unfolded will be provided within the individual study chapters. A summary of these activities provided below in Table 2.

Table 2: Summary of analytic methods and levels of co-analysis for each doctoral research work.

Study	Method of Analysis	Co-Analysis Involvement
Blue Sky Trust (BST): Study 1	Inductive Thematic Analysis	Sense-check of initial themes with participants and service provider representatives; final themes sense checked with representatives
National AIDS Trust (NAT)	Reflective Design	Sense-check of all research and design analyses was done with staff at NAT during research activities; reflective accounts were reviewed by NAT staff
4MNetwork (4Mnet)	IPA	Initial co-analysis conducted with a peer researcher, with final analysis additionally reviewed and discussed with organisational representatives and supervising academics

⁸⁴ This includes whenever participants were prompted to describe or discuss non-verbal research activities, such as design activities.

⁸⁵ Audio recordings were deleted once transcribed.

BST: Study 2	Novel visual analytic process informed by IPA and Visual Anthropology	Analysis guided by presentations of image meanings by individual participants and group discussions; final themes sense checked with representatives
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In each case, resulting themes and/or insights were critically discussed with representatives of the respective service provider, and with participants when appropriate. This allowed for the resulting language, images, and interpretations to be enriched with additional detail and description in relation to service design and/or delivery, further embedding analyses within a community-based approach.

3.5 Moving Forward

In this chapter I have built on the Contextual Review explicated in the previous chapter, identifying a methodological gap in explicit guidance relating to how ‘expert’ design praxes might work ‘appropriately’ within CBPD research. In response I outlined my novel theoretical extension for CBPD, Community-Based Co-Design Praxis, describing its four pillars (Coalition, Conversation, Co-creation, and Critical Ethics) and how they inform my methodological approach. I have set out this approach in relation to the theoretical concepts that provided its foundation. I then discussed how this approach connects to and extends from existing discourses and contemporaneous CBPD praxes, before turning to present an overview of methods utilised in my empirical studies and reflective accounts.

In the chapters that follow, I report on four doctoral studies (three empirical studies and one reflective account), presented in chronological order. Chapter 4 introduces an exploratory first study that illuminated experiences of peer support for women living with HIV attending a local peer support group. This informed my initial framing of what peer support services represent for women living

with HIV in the UK, how they operate, and how digital technologies are used within this context.

4 Exploring the Form of (Digital) Peer Support Interventions in Context: How Women Living with HIV Conceptualise and Use Peer Support Services

4.1 Introduction

In order to co-design appropriate digital social support tools and services alongside women living with HIV, I first need to understand what I am trying to design and how it works. This includes understanding the current digital tools used for social support service provision (e.g., peer support) for women living with HIV in the UK and how they work appropriately within their use context(s). This initial study addresses my first two research questions (RQs)⁸⁶, offering insight into how women living with HIV conceptualise and contextually use both peer support services and digital technologies (RQ1) and how peer support services in turn utilise digital technologies for service provision (RQ2). This chapter represents the first stage of an unfolding 'core of sense' that was co-created with my collaborators and continually developed throughout my doctoral studies.

⁸⁶ RQ1: How does lived experience impact on the conceptualisation and use of digital technologies by women living with HIV in the UK?

RQ2: How are digital tools and services designed and used within HIV social support services for women living with HIV in the UK?

This study responds to two study research questions (SRQs) – that is, RQs devised specifically for this study:

(SRQ1) What do women living with HIV value about peer support settings and services?

(SRQ2) How are digital technologies used in relation to the peer support group?

This study explores how digital technologies are used in relation to peer support by entwining insights into (1) how women living with HIV conceptualise and contextually use peer support services with (2) how these services and their clients use digital technologies. I build upon previous HIV research exploring peer support interventions with service users, which has highlighted how previous models of peer support may be limited by overlooking contextual factors and excluding infrequent cases (Peterson et al., 2012). An exploratory approach was deemed appropriate given the lack of representation of women living with HIV within published research on digital HIV peer support interventions, as outlined in my contextual review (2.1.3.2).

4.1.1 Study Aims

My aim for this first empirical study was to gain a contextual understanding of how women living with HIV conceptualise peer support and use peer support services and digital technologies, in order to inform the design of appropriate digital interventions in this context. I set out to learn *what* to design by (1) first understanding what peer support means for women living with HIV (SRQ1) and (2)

how digital technologies support or threaten valued aspects of peer support services (SRQ2)⁸⁷.

Although there is published guidance on best practices for HIV peer support service provision generally (Positively UK, 2017), there is currently no explicit guidance as to how these services should take shape or be otherwise facilitated *digitally*. Most examples of digital HIV peer support services, such as the ‘My Community Forum’ (Terrence Higgins Trust, 2021), are only available to registered members in order to establish them as ‘safe spaces’⁸⁸. These platforms are also unlikely to include users who have difficulties using digital technologies, or those who do not wish to engage with others through digital means.

Given this restricted access to many digital ‘safe spaces’, the importance of capturing a broad range of experiences, and the methodological importance of conducting research with communities (3.2.2), I chose to conduct this study with an in-person peer support group for women living with HIV. In doing so, my focus was on understanding how experiences unique to each service user relate to an overall shared ‘core of sense’ that includes both objective (e.g. economic) and subjective (e.g. personal experiences) considerations. I aimed to glean insight and inspiration into how a single service could be appropriate for a plurality of users, and how such a service might take shape when facilitated by digital technologies.

⁸⁷ Within design praxis these forms of understanding are often referred to as ‘framing’ or ‘defining’—using contextual knowledge (Framing) to inform the designed form of final outputs or activities (Defining) (Chung, 2019).

⁸⁸ While it may have been possible to request access to review private digital platforms such as ‘My Community Forum,’ this could encroach on the privacy and trust established within these platforms as ‘safe spaces’. This would create additional challenges for engaging in research ethically, as this admission could negatively impact the digital service unless discussed and agreed upon with all users, which could be unfeasible to do at scale.

4.1.2 Context of Engagement

Blue Sky Trust (BST) is a Christian⁸⁹ charity that has provided social support services for people living with HIV across Cumbria and the North East of England since 1992. Their services include peer support groups, skill training courses, hobby clubs, volunteering groups, and various educational events and courses. The organisation is based in Newcastle-upon-Tyne, established in a large, multi-use building just outside the city centre, which also houses a variety of other charitable or non-profit organisations and a large church. The organisation is run by a small number of staff members and several volunteers, some of whom are also service users.

BST was initially recommended to me by a senior clinician working in the Department of Infectious Diseases at the Royal Victoria Infirmary (RVI) in Newcastle upon Tyne⁹⁰. The clinician noted that he considered BST to have a longstanding track record of delivering excellent services, including peer support and programmes for women living with HIV. Various other staff members within the clinic echoed this.

I initially contacted BST via their general email address, introducing myself and my doctoral research to gauge their interest in being involved this work aiming to study digital tools and services for women living with HIV. The director of the organisation responded and invited me to meet in person at the organisation to discuss my

⁸⁹ While BST identifies as a Christian charity, they also clarify that their religious positioning does not impact their focus on providing services; noting that they “acknowledge the value and uniqueness of every human being regardless of gender, age, ethnic origin, creed or sexual orientation” (Blue Sky Trust, 2021).

⁹⁰ This department operates as the specialist HIV clinic for the North East, and therefore is the central hub for HIV care services in the area.

research further. This initial meeting led to arranging this first doctoral research study.

4.2 Method

4.2.1 Study Design

This study was planned through my in-person and email conversations with the director of BST and the coordinator of the BST women's group (herein referred to as 'BST staff members') over several months. This included stages of collaborative review of the study design, discussion questions, and study materials (e.g., information flyer, contact cards, and participant questionnaire).

BST staff members and I decided that I would conduct an hour-long, semi-structured focus group discussion (FGD) with members of BST's women's group: a weekly HIV peer support group for women. We co-developed FGD questions to explore what the women valued about BST's peer support services; how these services involved digital technologies; how the women used digital technologies in their daily lives; and any privacy concerns that the women may have about using digital technologies (see Appendix C.2.6). The women's group was chosen to represent the experiences of women living with HIV specifically, and for its regular attendance of 5-10 women at weekly group meetings. Participants in this group also already knew each other, making a FGD more feasible as relationships already existed.

The plan was for me to attend the women's group the week prior to the FGD to introduce myself, the proposed study, and distribute an information flyer⁹¹. The following week, the FGD would begin with me

⁹¹ The information flyer would allow for present group members and those not in attendance that day to learn more about the study in their own time.

giving a brief introduction about myself, the study, and the informed consent process (10min). After participant questions had been answered and consent forms were completed, there would be a 10-minute icebreaker where participants would be asked to introduce themselves. The main discussion would then be 35 minutes long, ending in a short concluding session to address final participant comments. Participants would be remunerated with a £10 shopping voucher. It was planned for the FGD to be audio-recorded, with the informed consent of all participants, for later qualitative analysis. After the session I would transcribe and anonymise the transcript, deleting the original recording once completed.

4.2.1.1 Ethical Considerations and Communication Design

The study protocol was reviewed by the departmental Ethics Committee at Northumbria University, along with considerations of risk and risk mitigation strategies. The Committee approved the study on 2 July 2018 (see Appendix C.1). Consideration of Critical Ethics (3.2.4) informed my decision to purposefully avoid using language or symbols referencing HIV (e.g. 'living with HIV' or a red ribbon) within printed information, contact, or consent forms given to participants to avoid accidental information sharing; and using future-focused language within FGD questions to avoid raising previous trauma for participants. The information flyer included in this application was reviewed by BST staff prior to its submission.

In preparation for the study, I also discussed with BST staff members how the situation would be handled should the FGD cause any emotional distress for participants. The director explained that the group's facilitators (the coordinator and another volunteer) would be present to sit with any distressed participant, and would provide support to them after the session. The director also recommended

setting some ground rules in terms of participants respecting each other and not speaking over each other at the start of the session.

Study Documentation Design

To inform the graphic design of my supporting documentation I conducted exploratory visual research into locally available HIV printed materials (as available at HIV and sexual health clinics in Newcastle-upon-Tyne) to familiarise myself with common visual language and symbols used in HIV visual communication materials (see Appendix B.1). I then used this insight to inform a series of visual branding experiments for this research project (see Appendix B.2) that I discussed with my supervisors. I made a final selection based on the concept of keeping research 'future-focused' and positive. This conceptual focus was informed by my early conversations with BST staff on the focus of the FCD. This branding was then used to design the information flyer (see Appendix C.2.2) and discrete contact cards (see Fig. 5 below).



Figure 5: Researcher contact cards using visual branding. Photo by Author.

4.3 Procedure

4.3.1 Pre-Study Session

I organised attending a regular women's group meeting prior to study commencement, in order to introduce myself and the study, and to give out the information flyers for consideration; and to give group members the opportunity to ask questions about what taking part would involve. The FGD was scheduled for 3 July 2018 to allow for the ethics application to be processed. The following excerpt illustrates this initial pre-study meeting.

Pre-Study Session

I arrived at BST at 1pm on 19 June 2018 for the pre-study session with the women's group. I signed in at the front desk whilst the building secretary called the coordinator of the women's group, who came downstairs to greet me. After introductions, I followed her through the building, passing by an English language class, and climbing up an old wooden staircase. Two floors up, we arrived at a small landing and walked through a door, its sliding plate moved to read 'IN SESSION'.

We entered the large main space at BST, and I immediately noticed how bright and colourful the room was. It was filled with light, streaming in through a wall of old windows that wrapped around its longest side. Each wall was painted with a different bright colour, coordinating with the bright colours of other things in the room. At the centre of the room were several large sofas, each adorned with vibrant covers and pillows, arranged in a circle. A large circular coffee table sat in the middle of them with some smaller side tables positioned near the sofa arms; one had an iPad connected to a small Bluetooth speaker, which was quietly playing songs from a Spotify playlist.

To the left of the couches, there was a small kitchen counter, some comfortable chairs, and an open storage cabinet filled with labelled boxes and baskets and topped with various information booklets. To the right of the couches there was a table with two chairs topped with a patterned plastic sheet, laden with art supplies and flanked by closed cabinets. Throughout the room there were several tall and healthy green ferns, placed around otherwise empty corners, as well as a few decorative floor lamps. The walls were covered with paintings, schedules, and what seemed to be pieces from previous group activities, like listing personal strengths on colourful pieces of card. The room was otherwise empty except for one woman, who I was introduced to as a BST volunteer who helped run the women's group.

Near the counter a small table had been filled with platters of fruit and vegetables, bowls of crisps⁹², and various sandwich spreads with slices of bread. The coordinator asked if I would like a cup of tea and invited me to make myself at home and get some food. I accepted and chose a few pieces of fruit, wanting to be polite but not taking too much from the spread meant for the women attending the group. As we chatted women slowly started entering the room, greeting the volunteers and each other warmly as they made up plates of food for themselves and settled in. The women were generally in their fifties or older, some moving slowly or with mobility aids, and all greeting everyone they knew in the room upon entering. The atmosphere was warm and lively, like meeting friends at a favourite coffee shop.

⁹² Potato chips

When it appeared everyone had arrived, the coordinator announced that the meeting would be starting soon and gathered all the women on the encircled couches. Everyone got themselves settled, and several women were checking their mobile phones or plugging them into wall chargers whilst chatting with each other. The coordinator then introduced me, and I proceeded to introduce myself, my research, and the planned FGD. While I spoke, I went around the circle to hand out an information flyer to each woman so that they could review it at their own pace. Various women commented that they liked the design; I was glad that I had chosen to use various bright colours and a brochure layout to make it more interesting (see Fig. 6 below).



Figure 6: Photos of the *information flyer for the BST FGD* (clockwise from top left): front cover, inner pages, outer pages. Photos by Author.

After I had finished, the coordinator opened the discussion up to invite any questions that the women might have about the study.

The women voiced interest in participating. There was shared agreement that audio recording the FGD would be acceptable, so long as individuals could choose not to be recorded (I would take notes while the recording was paused for these participants). After a while, and with no further questions about the study, the topic of conversation changed, and the women began to hold various conversations amongst themselves. I thanked the coordinator for introducing me to the group, and she invited me to stay for the rest of the session to get to know everyone.

I spent the next hour meeting several of the women, introducing myself and learning more about them and how their weeks had been. At around 3pm the women started to leave, collecting refunds for the various modes of transport they had taken to get to and from the meeting from the other BST volunteer. She recorded costs and collected receipts in a binder, providing refunds and change from a small metal cash box. Once everyone had left, I thanked the volunteers and saw myself out, signing out at the front desk.

4.3.2 Focus Group Discussion (FGD)

The FGD took place on 3 July 2018. I ran the FGD with support from two BST volunteers (the coordinator and supporting volunteer) and my Principal PhD supervisor, Abigail Durrant. The first 30 minutes of the session were spent on introductions and talking through the consent form, with the volunteers, my supervisor, and myself assisting participants who had difficulty completing the forms. The FGD took place over the following hour after a short break.

The FGD included a series of questions, presented in a semi-structured format. I have included the FGD questions, developed with

representatives from BST (as described in earlier in 4.2.1) below for easier review (For full topic guide see Appendix C.2.6).

Session 1 Topic Guide: Main Session

1. What do you value about this (BST) kind of peer-to-peer setting?
 - a. Are there other ways that you achieve these values?
 - b. What is it about these things that you value (e.g., what is it about "friendship"?)
 - c. How else is this facilitated (e.g., how else do you experience friendship)
 - i. How does technology help (if at all) with this instance as well?
 - d. How could technology aid these values?
2. What kind(s) of technology do you use in everyday life?
[provide a visual list/prompt to review list in survey]
 - a. Discuss as an open conversation, or potentially go around the circle is people are quieter
 - b. Could lead to people saying they don't use technology very much; if so, enquire about why, potentially learn about fear/concerns from this
3. What sort of privacy concerns do you have (general)?
 - a. Why? (May come up in prior question)?
 - b. Do you have any privacy concerns about technology?
 - c. How can technology help and/or make these concerns worse?

The FGD concluded with a brief wrap up and summary, in which participants were thanked for their time and reminded of: (A) how they could get in touch if they had any questions or wished to talk more; (B) their right to remove their consent from the study (and how to do it); and (C) how findings would be applied and distributed to them after an initial analysis (this process is described further below in section 4.4).

4.3.2.1 Participants

Participants for the FGD were recruited internally from the women's support group at BST using convenience sampling. Prospective participants were informed of the study by BST staff and volunteers and given a short presentation on the study (the pre-study meeting described previously) by me. Attendees of the women's group on the day of the FGD who had not attended this pre-study session were also invited to join after being informed of the study.

The discussion was attended by eight women living with HIV (see Table. 3). Participant demographic information was collected using participant questionnaires completed at the start of the study session.

The women were aged 35-66 and had lived with HIV for 7-28 years. Ethnicities of participants varied and included women who identified as African [n=4], White British [n=1], and British [n=1]; two participants did not give their ethnicity. All participants provided informed consent to participate in the study and be audio recorded.

Table 3: BST FGD participant demographics, collected in the participant questionnaire.

Age	Ethnicity
40	African
50	Not available
66	White British
64	British
55	Not available
59	African
51	African
35	African

4.4 Data Processing and Analysis

Audio recordings of the FGD were safely transferred from the study site to a secure Newcastle University server, for processing and storing separately from participants' identifiable information; consent forms and other identifiable information were stored in a locked cabinet at the University. I transcribed the FGD recording and demographic information collected, deleting the original files once anonymised.

The study transcript was analysed using an iterative process of Inductive Thematic Analysis (Braun & Clarke, 2006). In taking an inductive approach, this iterative analytic process was positioned to broadly explore the topic of peer support as voiced by participants; illuminated themes being informed by the data itself and a joint analytic review process rather than a being driven by a specific theoretical or analytic interest. In line with my community-based approach, we agreed that an analysis of the transcript would be fed back to BST and participants for member checking prior to being finalised. I chose to present the analysis after initial coding and thematic grouping, to allow for a less time-intensive review process and support discussion on illuminated themes.

I first used NVivo (a qualitative coding software) to develop codes from the anonymised transcript, reading through the transcript several times. I then grouped codes into several initial themes before arranging to meet with BST's director and the women's group on 4 December 2018 to review the initial themes. Both the director and members of the women's group attending (5 total; 2 who had attended the FGD and 3 new women) commented that the themes reflected their experiences, expanding on some themes with examples from their own experiences with BST.

After the BST review, themes were then further defined through a joint anonymised data analysis session with two of my PhD supervisors (Abigail Durrant and Lynne Coventry). Codes and themes were mapped (see Fig. 7-8 below) before being reviewed in a second joint anonymised data analysis session with myself and three other academic colleagues with experience conducting qualitative design research in sensitive contexts, whom approved of them with the request that theme names be adjusted to more accurately reflect the language used in the transcript. Final themes are defined and expanded on later on in this chapter (4.5).

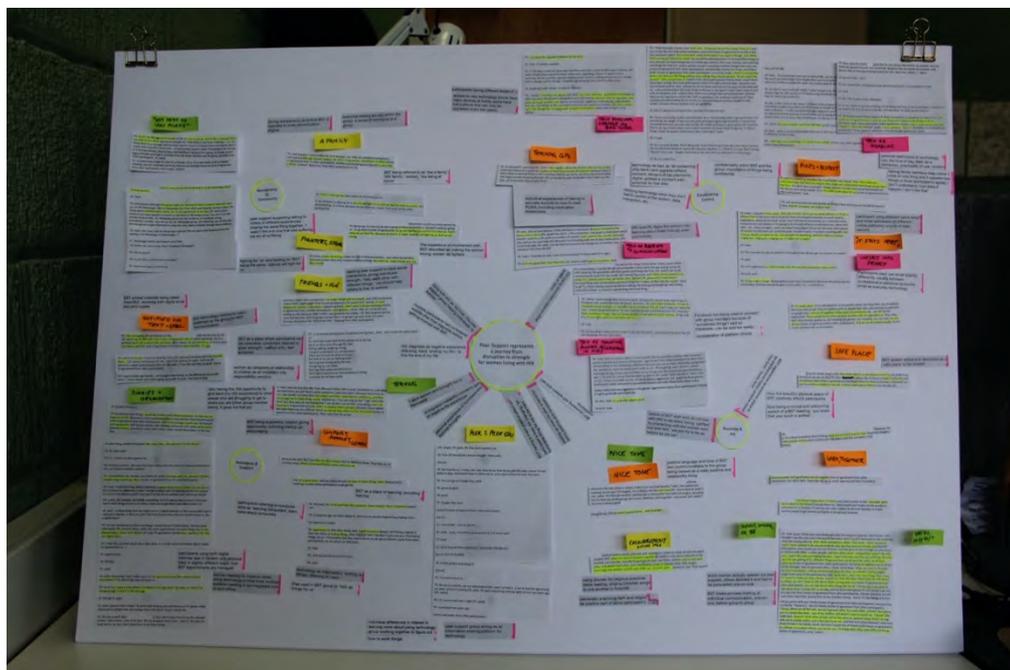


Figure 7: Thematic Map of BST FGD. Photo by Author.

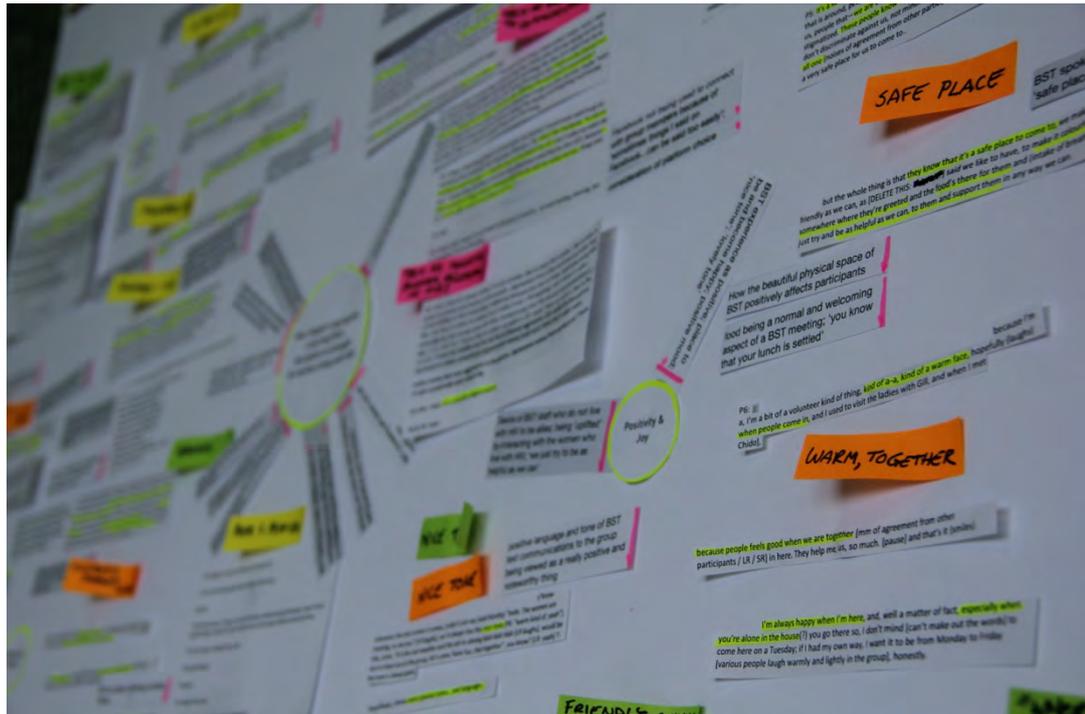


Figure 8: Detail of the *BST FGD* Thematic Map. Photo by Author.

4.5 Findings

I now describe the resultant themes from this study. Participants' contributions have been anonymised, their names represented by [P#]. The structure of the themes reflects the voiced conceptualisation of peer support, firstly, with the thematic narrative of peer support as a journey to strength, and subsequently with three major themes related to valued aspects of peer support as Family, Friends, and Fighters (see Fig. 9). Insights into valued aspects of peer support (SRQ1), and the use of digital technologies in the peer support group (SRQ2) are presented as subthemes to illuminate how they connect to these broader themes. In the following subsections I contextualise findings by referring to extant research when appropriate, in order to reinforce a foundational understanding of this complex design space.

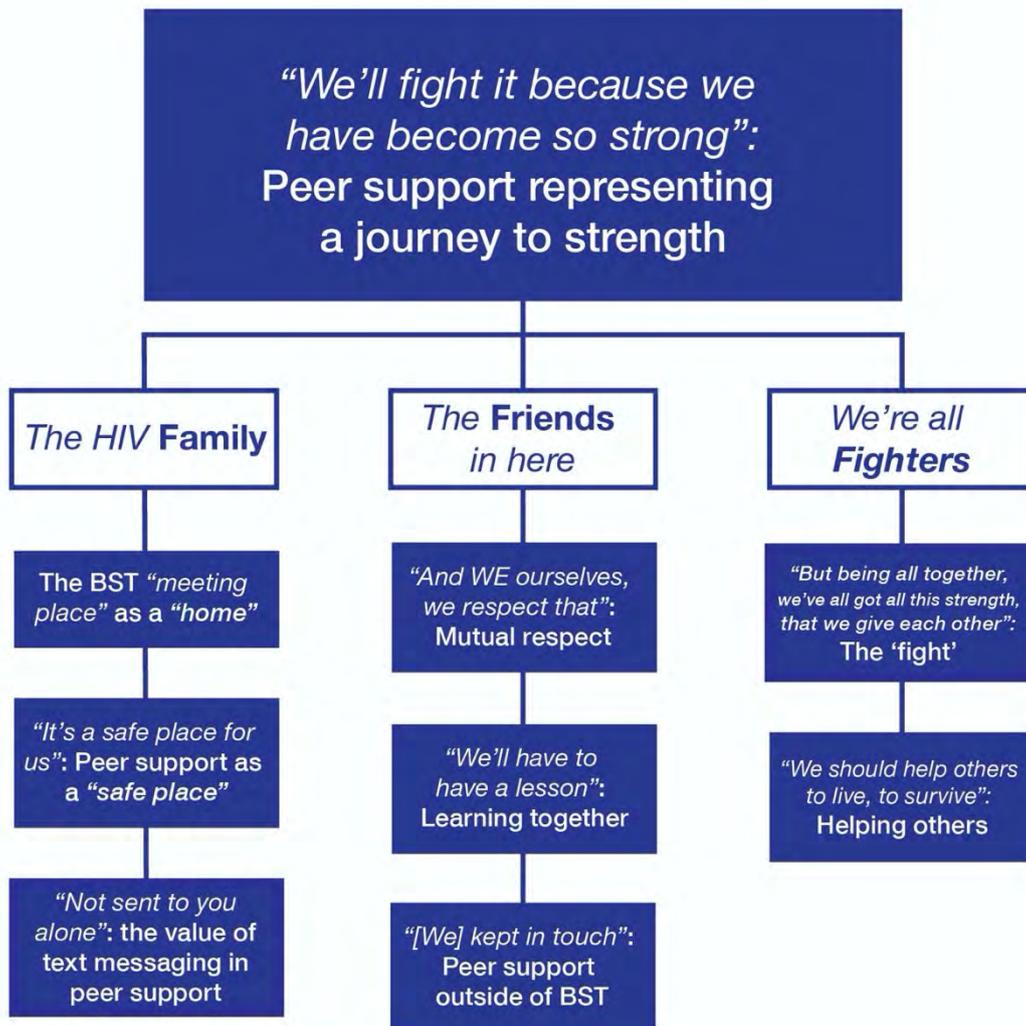


Figure 9: (From top to bottom) Resultant thematic narrative, themes, and subthemes of the BST FGD. Image by Author.

4.5.1 ***“We’ll fight it because we have become so strong”: Peer support representing a journey to strength [Thematic Narrative]***

The central thematic narrative repeated through participant’s personal stories and responses was the journey from disruption and distress to strength through their involvement with peer support. The deployment of journeying metaphors when discussing experiences of HIV peer support services has also been reported within recent

community-based research in Canada (Switzer et al., 2020); the authors describing it as an apt metaphor for the dynamic and relational process of peer support engagement.

Several participants voiced having extremely negative experiences at the time of their HIV diagnosis, considering the change as “*the end of my life*” [P8]. Two participants recounted their experiences of suicidal thoughts at the time [P4, P7]; “*I just didn’t feel like meself (sic) anymore...felt like really all over the place, frightened, scared*” [P6]. Participants who spoke of suicidal thoughts also discussed other major stressors in their lives at the time, such as seeking asylum, homelessness [P4] and estrangement from children [P7], which added to the disruption that HIV had caused in their lives. This echoes previous research with women living with HIV in the UK, which has highlighted how difficulties relating to HIV can be intensified by structural and social factors, such as poverty, poor housing, immigration status, and relationship breakdown (Flowers et al., 2006; McLeish & Redshaw, 2016; Tariq, 2013).

While some women spoke of a sense of biographical disruption (2.3.3.1)⁹³ upon their HIV diagnosis, one participant also spoke of the disruption as more of an issue in relation to her social support networks, rather than her sense of self. She described how she had no one local to her to talk about her experience living with HIV after moving to a new area: “*(W)ith no one to talk about my HIV, only when I ring my family back home and then, that was it.... I said no I can’t live like that (laughs); I needed to find support*” [P5]. As someone who had moved to the UK for education, P5 found BST’s

⁹³ Biographical disruption is defined as an interruption to “the expectations and plans that individuals hold for the future”, requiring “a fundamental rethinking of the person’s biography and self-concept” (Bury, 1982, p. 169).

peer support services to be useful as a means to access community within a new location.

Viewing these initial disruptions as past events, participants then spoke of their gratitude for the services and support provided by Blue Sky Trust, emphasising how this had helped them reach their current positions of strength: *“It’s a safe place; it’s a place where you get nurtured, you get encouraged. You get to grow from the person, probably back to the person you were before. But even more better and more stronger”* [P6]. One participant summarised the experience *“...they comfort me, they give me strength, they give me my life back”* [P4]. The evolution from a place of disruption to strength through peer support is also expressed in a poem one of the participants chose to share within the FGD, which she had written in a personal journal and shared with the group previously:

*As I sit in this room with all the women of our group,
Say hi as they come through the door,
Sitting, talking, laughing, crying,
Trying to understand our predicament.
There are no cure for what we have,
But look at us, we are fighting back.
We’ve grown strong along the way,
Not giving up, not today.
Each day that comes we [hit] it on,
We’ll fight it because we have become so strong.
Look how far we have come. [P7]*

While various instances of informational (e.g. advice) and instrumental (e.g. money for transport to/from the meeting) support were observed, the women largely spoke of the importance of emotional support when discussing their journey with peer support. As described in P7’s poem, this emotional support was mainly derived through social interactions within the group.

Beyond service use, some participants also felt their journey to strength had been further developed through additional involvement within BST as an organisation: [P5]: *“I knew that I had the capacity to live with my HIV, [through] support from Blue Sky Trust and coming to meet with people who understand your situation, and also having the opportunity to give back to other people who are struggling to get to where you are...it gives me that joy”* [P5]. The women highlighted this additional involvement specifically in reference to BST’s specialised mentorship training opportunities, both for peer support⁹⁴ and involvement within external General Practice (GP) training programmes⁹⁵. This move, from a client of BST to a contributor within the organisation, was described as something to take personal pride in. As P5 explained: *“...Blue Sky Trust also give us the opportunity... to train us to become mentors who would also support other people in the organisation who are working towards standing on their feet. So it’s an honourable thing for me to be here”*.

Participants related the experience of teaching and supporting others through mentorship to their past experiences of disruption. P4 explained that being involved in mentorship and training activities was important to her *“because I know where we come from was very difficult, but we should help others to live, to survive”*. In this way, the journey from disruption to strength through peer support not only provided a path for individuals to grow stronger themselves, but also the potential for the women to support others; repositioning themselves from the one being supported to one providing support

⁹⁴ BST provides a training programme for clientele to become peer mentors for others living with HIV.

⁹⁵ Programmes are run within local hospitals and medical programmes in the area to facilitate training presentations for medical staff and students to learn about personal experiences of people living with HIV attending clinical and GP services. This training is to help address issues around the treatment and discrimination of people living with HIV within clinical settings. While BST does not facilitate these programmes, they are aware of them and involved as a part of the larger network of HIV care providers in the region.

over time. This echoes the importance of peer support as stated in BHIVA's⁹⁶ 'Standards of Care for People Living with HIV,' which described "peer support [as] a key contributor to optimising self-management as it not only draws on community resources and expertise but allows people to contribute to communities" (British HIV Association, 2018, p. 17).

4.5.1.1 This is a family; here I've got lots of friends; we fight for each other to survive: Mapping values within peer support

Participants continually identified as members of a community, in addition to seeing themselves as being on an individual journey, by attending peer support as a service user. This sense-making illuminates the unique value of peer support as a social support service delivered via interpersonal communication (e.g. socialising), while also straddling the line between created (networks supported by explicit interventions) and embedded (networks formed through social relationships) peer support social networks.

This reflects the more holistic definition of social networks within HIV peer support proposed by Jennifer L Peterson et al (2012), wherein they can be considered more broadly in relation to how people living with HIV can receive peer support in various forms: a peer can be someone you meet within a peer support meeting and/or a friend or family member living with HIV outside of that context. Their study highlighted that embedded network peer supporters (when peers are family or friends) are viewed as having distinct advantages as an effective peer support strategy (Peterson et al., 2012). Some created peer support networks, such as weekly group meetings, may intentionally blur the lines between personal social engagements and

⁹⁶ The British HIV Association (BHIVA)

service provision, helping to strengthen bonds between service users and potentially facilitate the creation of embedded peer support networks that may exist alongside or outside of service provision.

While familiar terminology was used (e.g. sisters, family), indicating friendly social bonds had formed in the group, exact terminology differed throughout the FGD. Three main identity types (Family, Friends, or Fighters) were illuminated when mapping codes into themes during analysis, forming the three major themes within the overarching thematic narrative. Whilst all three relate to the social networks of peer support, they also presented three distinct categorisations relating to specific valued aspects of it. In order to present key values and associated aspects of peer support (including those that involve digital technologies) identified by participants, I have used these three identities as themes, mapping related insights as subthemes.

4.5.2 Theme 1: The HIV Family

The community within BST was often referred to as a Family, *“...they’ve been supportive, they’ve been [pause] like a family”* [P5], with the meeting space within the organisation viewed as a home: *“To me, it is like coming... home. It’s like being at home; y’know you’re with your family. Because this is a family. Y’know it’s... the HIV family”* [P7]. The framing of peer support as “family” or “home” was often used when referring to values of safety, support, and caring⁹⁷. Participant 4 [P4] also spoke of the ongoing comfort and support that she had received at BST:

“When we came here, [BST] said “here’s some [facial tissues], wipe your tears”, because every time we cry. Like myself I cry every time. But when I was here [they] comfort us, and they

⁹⁷ The metaphor of a ‘house’ has also been previously used to conceptualise the various themes and priorities raised by women living with HIV around sexual and reproductive health and human rights globally as a ‘safe house’ (Orza et al., 2014).

encourage me to make things, easier. Sometimes I “You can only do this” “Ugh I don’t like that” but, they said, uh, the feeling that “I can do this I can do this,” [I can do] everything.” [P4]

P4’s utterance highlights how she had received comfort and encouragement from BST’s peer support service whilst navigating difficult experiences, supporting a greater sense of ease in her life. Feelings of support, comfort, and ease were often voiced by participants, related to their conceptualisation of the peer support group as a caring and nurturing Family.

For P7, the value of peer support as a family included physical interactions, such as hugging and kissing, that some of her biological family members had refrained from as a result of misconceptions and stigma around HIV:

“[BST is a place] where we all feel safe, we can hug each other, kiss each other, y’know? But where you’re outside that door... one of my children still doesn’t want to touch me. She holds back. Aaaand (sic) I think other people will be the same so, (pause) I keep what’s wrong with me to myself, and to, just a few that know me.” [P7]

While her previous negative experiences with her daughter had led to concerns about how other people might react, P7 valued peer support as a space in which these concerns were not an issue; where she could openly give and receive affection.

This participant also expressed that this affectionate and caring atmosphere was reinforced through the friendliness of the group at BST:

“When we come in through this door everybody’s smiling and when we leave the door, everybody’s smiling (slight laughs from some of the other participants), and I think that’s, that’s the main thing; that’s how it’s meant to make you feel.” [P7]

A sense of happiness was echoed by Participant 3 [P3], who shared that she had enjoyed continuing to come to the group in part because the sense of togetherness it fostered:

“I know everybody now, since last year I don’t know, two years ago I come here (mhmm from other participants) and I loved it so much...because people feels (sic) good when we are together in here. They help me, us, so much.” [P3]

Friendly interactions amongst peers were seen to create positive experiences for all members, further supporting the feelings of support, comfort, and ease and conceptualisation of the group as a Family.

The thematic categorisation of the peer support group as a Family was further strengthened by three key service features, described below as subthemes: the physical “meeting place” as a ‘home’, the peer support group as a “safe place”, and text messaging as an extension of the group’s affective function within clients’ daily lives.

4.5.2.1 Subtheme 1.1: The BST “meeting place” as a “home”

The sense of BST as “family” or “home” was further strengthened by the physical space weekly meetings took place in, which enhanced feelings of ease and comfort. Participant 5 [P5] highlighted this, explaining:

“[T]he meeting place especially ...[BST] knew they had to make this place, the meeting place for their clients, homely. (“mmm” and “yeah” from group) and it was so colourful—when I entered I said “I don’t want to go away” (laughs) I want to stay here! The colours were so beautiful and there were plants everywhere and, y’know, it was just so nice.” [P5]

The interior design and decoration of the BST meeting space was viewed as an important aspect of the ‘home-y’ environment, aiding the positive and easy socialisation it housed. P5 also described how an instrumental service provided by BST, a free lunch, snack, and beverage provision during the peer support sessions, further added to this mood:

“And there’s always food in Blue Sky Trust (a few people in the group laugh). You feel hungry, it’s lunchtime, and you know it’s a meeting day you, you just know that your lunch is settled (some group members laugh).” [P5]

The overall sense of comfort and ease associated with peer support sessions was enhanced by the physical meeting space and regular activities (such as lunch). These aspects of service provision were described as unique features, contributing towards a sense of 'home' in relation to peer support sessions: a place of comfort, ease, and support.

4.5.2.2 Subtheme 1.2: "It's a safe place for us": Peer support as a "safe place"

I found that the sense of trust established between service providers and clients at BST further strengthened feelings of support, comfort, and ease voiced by participants. BST and the women's peer support group were perceived by all participants as a "safe place," where clients knew that they would not be stigmatised or otherwise discriminated against.

"It's a safe place. It's a safe place for us to come to, where we know that everybody that is around, people that are walking with us, people that... volunteering to walk with us, people that—we are all together in the same circumstances, we... we will not be stigmatised. These people know what we have and they will not stigmatise us. They, they don't discriminate against us, not minding our, gender, our sexuality, our, our race; we are all one (noises of agreement from other participants). And we are all treated equally. So it's a very safe place for us to come to." [P5]

All participants expressed their understanding that the foundation of BST as a safe space was the rules set in place by the organisation itself to protect their clients:

"It's something that Blue Sky Trust hold[s] very dearly...they make you understand that, [from the] first time you step in, they make you understand, that things [that go on in] here stay here. You don't discuss people's things, and you should understand that people not also discuss your thing outside. So, it, it's really a safe place for us." [P5]

The rules used and respected within BST were found to help participants feel comfortable and at ease when speaking with others,

as they could trust that they would be respected that nothing would be shared outside of the group.

The freedom that such a “safe place” afforded was voiced as important. P7 explained that she felt free to talk about anything, whether it was an-specific HIV topic or not, knowing that her privacy and confidentiality would be respected:

“Y’know, it gives you that safe place where you can talk about anything, you don’t have to talk about what’s wrong with you [noises of agreement from other participants], you can talk about other things like we do, y’know, but if we need to talk about what’s wrong with us we can, and we know that [pause] it’s not going to go out through that door [noises of agreement from other participants], y’know whatever we tell each other stays here.” [P7]

P7 described how this feeling of safety afforded her a sense of ease in socialising with others at BST, a feeling that other participants said they related to. This also allowed all topics to be considered equal, meaning HIV-specific conversations were the same as any other—a comforting reprieve from other social contexts in which HIV may be potentially exceptionalised and stigmatised.

The importance of protecting individual confidentiality led some group members to purposefully not communicate with other members on social media platforms, such as Facebook, to avoid unintentional sharing HIV information. As described by P6:

“I think, I think though they’re all very good, but [pause] I would never want to go on Facebook with somebody from the group. Because... I think sometimes things I said on Facebook and can be said too easily and... it’s not right; cause it’s out there isn’t it...so you’ve got to be sort of careful... so yeah texting, phoning, but not Facebook.” [P6]

In this way the “safe place” of the peer support group at BST was carefully managed in relation to the digital technologies utilised for service provision. While participants described that text messaging and phone calls were regularly used as means for BST to

communicate with individual clients, they also highlighted that connecting on social media platforms was not, as it could potentially led to unintentional information sharing.

Maintaining the peer support group as a "safe place" for service users was seen as a key service priority, as it helped facilitate the support, comfort, and ease experienced by participants. It also informed the limited the use of some digital technologies, such as social media, within the group while informing the use of others, as described in the next subsection.

4.5.2.3 Subtheme 1.3: "Not sent to you alone": the value of text messaging in peer support

Some digital technologies, such as texting and emails, were used by BST service providers to remind group members of upcoming meetings or events. The value of friendly and warm interactions through these channels was raised by several participants, connecting this digital technology use to the valued aspects of peer support services within the Family theme. Participant 5 [P5] highlighted this in relation to the tone of text messages (SMS) sent by group organisers to individual group members as reminders of upcoming events or meetings:

"Text messaging, like um (pause) um like [P7] said, has become a good way for Blue Sky Trust to also communicate with us; like in a general way to tell us about their, activities, tell us about... remind us, or to just wish us well this warm weather, it's nice. Y'know whenever the text comes it comes, it don't just say [said bluntly] "hello. The women are meeting, so see you." No! It always has this nice tone [P6: warm kind of, yeah]. Like, umm, "it's the cool weather and the sun is shining blah blah blah, would be nice to have you at the group, let's come, have fun, chat together", you know? The tone is always good.... Those lovely, y'know sweet (pause) tones... and language." [P5]

In this way BST were found to use text messages as an extension of the group's affective function—using similar language and sense of

familiarity as a means to further embed the feelings of comfort generated through meetings, within client's everyday lives.

Further to the importance of a positive and warm tone within text messages, P5 also described the impact of knowing that these text messages were being sent to others in the group, even though the messages were sent individually rather than to a group chat:

“So it’s not like we communicate on the [text messaging platform], it’s not our group. But it’s like, a message that is not sent to you alone, [giving an example as] “Hello [P5] we have a meeting...” you know that it’s a message that has been sent to a bunch of people, and it has that lovely tone... so every week... every Monday you’ll get a reminder from the lovely [BST group coordinator] who runs the group.” [P5]

P5 explained that receiving these text messages individually did not take away from its value as something sent to others, as it was a conscious choice made to respect the confidentiality of members:

“Although the group might not necessarily have to interact with each other on, on the Messenger, like on WhatsApp... but then, the thing about confidentiality which is very paramount in our days... unless if you have people’s consent to add them...you don’t just add people.” [P5]

This decision balanced the importance of knowing text messages were being sent to others with maintaining individual confidentiality; carefully retaining the distinction of BST as a created peer support network that some clients may be wary of being connected to outside of weekly meetings. In this way, text messaging helped extend the affective function of the group beyond in-person service provision by creating positive experiences in clients' daily lives whilst maintaining a sense of confidentiality.

4.5.3 Theme 2: The Friends in Here

In the recorded session, participants often referred to others as “friends” in addition to describing the group as a “family”. Friendship was portrayed with nuanced differences from Family, as it more often related to the participants' relationships with individual members

rather than their relationship with the whole group; ‘I have friends’ compared to ‘we are a family’. One example of this can be seen in Participant 2’s utterance: *“when we are here, everyone explain[s] their own, situation and everything. We make fun, make friends and, [are] just like a family”*. While P2 refers to the overall environment being “like a family,” friends are relationships made by the individual members. This distinction also highlights Friendship as an *active* relationship—one actively chooses their friends, whilst they experience the feeling of being “like a family” passively.

While the distinction of Friends being a self-led relationship type treads the line between being a created or embedded peer support network, valued attributes within the Friend theme were not necessarily voiced as being embedded outside of service provision. This nuance can be seen when P7 spoke of the differences between her relationships within the peer community compared to her friendships outside of the group:

“I’ve made friends with everybody [here]...I only have three friends in my whole, world. But here I’ve got lots of friends [soft noises of agreement from other participants]. So, y’know, it is a place where, you can be, you. And help each other with different things.” [P7]

In this way valued aspects of peer support within the Friend theme can include both individual-led relationships within created peer support networks and/or embedded social networks.

While Friend relations were often used in utterances involving values similar to Family (such as comfort, ease, safety and support), these values were used more in relation to active, self-led interactions rather than the more passive interactions related to “family” or “home”. These active values, such as mutual support, echo the importance of peer support within BHIVA’s ‘Standards of Care for People Living with HIV’ as a means of addressing the social isolation caused by HIV-related stigma (British HIV Association, 2018). Mutual

support, for example, helps facilitate identified benefits of peer support such as “social inclusion and well-being” and “allow[ing] people to contribute to communities” (ibid., p.17).

Distinguishing the active, self-led aspects of the peer support journey within a separate Friends theme, as opposed to peer support as Family, highlights three key actions valued by some participants: (1) the act of ‘mutual respect’, (2) ‘learning together’ through informal knowledge exchanges, and (3) choosing to ‘keep in touch’ outside of the peer support group. These subthemes highlight how these self-led acts draw from the tools and techniques facilitated by BST’s formal (‘created’) peer support services.

4.5.3.1 Subtheme 2.1: “And WE ourselves, we respect that”:

Mutual respect

Feelings of ease within the peer support group in relation to confidentiality and privacy concerns were discussed in relation to mutual respect; an action informed and supported by the rules set in place by BST. While these rules established the group as a “safe place” (as discussed in 4.5.2.2), the decision to follow these rules is an *active* individual choice for each member, aligning it more with the conceptualisation of Friends than Family. As described by P5: “we know that everything that we bring in here, stays in here; And WE ourselves, we respect that”. This respect helped support individual relationships by easing the barriers to interpersonal communication (such as HIV-related stigma) through shared understanding of living with HIV. P5 explained further:

“[When I am here] I feel like I meet my friends, because when I am here there’s nothing to hide (other participant’s “mhmm”, agreement noises), because we are all in the same situation. No one going to tell anyone outside, it’s all confidential here. So I’m happy, and [feel] safe when I’m here.” [P5]

Whilst P5 expressed how confidentiality was supported first by the rules created at BST, her description also sheds light on how this

valued aspect of peer support involved the active act of mutual respect between “friends”. In this way, the mutual respect that enforced the group’s confidentiality appeared to be facilitated more by the active individual relationships (Friends), fostered within the Family environment, than the rules themselves. This nuanced distinction highlights how individual-led acts were described as growing out of the environment and structure afforded by Family features of peer support services.

4.5.3.2 Subtheme 2.2: “We’ll have to have a lesson”: Learning together

In addition to the educational events provided by BST (e.g. workshops), the peer support group members talked about fostering more informal knowledge exchanges that could be used to inform future events. This kind of peer-led exchange was observed when members discussed a specific HIV drug interaction app, and getting apps on personal mobile devices in general, during the FGD:

P5: I came to find out about a drug interaction app, which you can have on your phone. So that anytime you go to the hospital, for a visit, [and] the GP prescribe[s] a medication for you and you’re not sure if it will interact with your HIV medication (“mmm” from other participants), you can just go on the app, put the name of the medication, and then you do all the checks and it will tell you the interaction. Some are just slight interaction[s] and you might take the medication, but if it will highly interact with your medication you will now draw the attention. “umm no, [that] medication will interact with my HIV medication, and this is based on this app”...

P6: But how do ya, I mean, can I ask, how do ya, how do you get this app—cause I’m not good at apps, someone’ll have to show me at, once upon a time not now, but soon...

P5: You just go on Google Play... [the] Google Play store.

P3: I would like [to know] how to do this.

P6: yeah... yeah. It would be good, wouldn’t it, to know yeah

P3: yeah.

P6: We’ll have to have a lesson on, how to get this app up.

Informal educational exchanges like this one exemplify how peer support may operate as a means for individuals to optimise self-management by drawing upon community knowledge and resources (British HIV Association, 2018). Knowledge exchanges such as this also support individuals to actively define areas of interest for the group at large, which may inform future educational events at BST.

However, these exchanges also highlight why this kind of self-optimisation is so important in the everyday lives of participants. When describing this app to other group members, Participant 5 described her personal experiences:

P5: But if [a new prescription] will highly interact with your medication you will now draw the attention [to your doctor]. "umm no [that] medication will interact with my HIV medication, and this is based on this app" and... they will have to look into it. Because sometimes the doctors don't check (P6: yeah they don't...) the interaction. I was [once] given a medication which (pause) I took for a, for quite a-a number of months, until I went to the, my HIV clinic and they said no you can't take this because it is interacting with one of your medications, (BST volunteer: Really? P6: yeah...) so we have to stop you and change you on another one, and I was given that from the GP!

P6: Yeah I-I find that as well, I was on [drug name] for ages...

P5: So it was good that I now have that app on my phone, yeah.

In cases where non-HIV specialist clinicians are unaware of HIV drug interactions, sharing knowledge about such resources amongst peers is of paramount importance, as care providers themselves may be unaware of them. In this way knowledge exchanges within peer support may help inform self-management strategies for individual service users navigating imperfect health and social care systems, creating community knowledges to help support one another.

4.5.3.3 Subtheme 2.3: “[We] kept in touch”: Peer support outside of BST

Although some forms of communication outside of the "safe place" of weekly meetings (such as connecting on Facebook) were not desired with friends from the group for reasons of confidentiality (see 4.5.2.2), some instances of connections made within the peer support group appearing outside of the group itself were apparent. These instances highlighted how some group members used digital technologies for supportive, self-led interactions with peers. In discussing how text messaging with individual members could be appropriate, Participant 6 described how she had used her mobile phone to stay in contact with another group member whilst they were both in the hospital:

“I think, by texting it’s alright... when I met [another participant], [we] kept in touch. But when we were in hospital together we used to... we used to text each other, and phone each other, and sing Christian songs to encourage one another and lift each other up.” [P6]

P6 and another group member had used their mobile phones to maintain communication outside of the created peer support group, providing a digital channel for them to support each other while in the hospital together. In this instance a passively ‘created’ peer social network (the group) had helped facilitate an individually-led ‘embedded’ social network (a friendship) outside of service provision; This embedded network using similar digital forms (phone calls, text messages) as those used by the women’s group to mediate peer support between members. As previously raised, while created social support networks may not preclude the creation of embedded social networks, equally they do not exclude them and indeed may help facilitate them. This instance again highlights how acts of peer support led by service users draw upon tools and techniques facilitated by created peer support services.

4.5.4 Theme 3: We're All Fighters

Participants often used concepts of strength, fighting, survival, and being 'fighters' when talking about their journeys living with HIV within the peer support group. Within these narratives the women often referenced how their lives had been dramatically changed for the better through their involvement with BST. As described by Participant 8:

"I've been so happy because... if not this group I don't think I could, I would survive it. [noises of support from some of the other women] I don't think I would still be here today. They give me back... they give me strength, and... just living today... it feels great." [P8]

Similar narratives about the positive impact of peer support services for people living with HIV have been described in previous research, including within work focusing on the experiences of women living with HIV (Wizinsky, 2019). These utterances highlight how experiences have changed for the better for participants as well as their ongoing need to continue moving forward in their lives. This is a nuanced extension from the Friend category, moving from active relationships and choices to a course of ongoing action—choosing to act as a person actively affecting the world around them as a Fighter.

Participants described the strength received through involvement at BST as stemming from several aspects of peer support, including both delivered services and the emotional support provided by staff, volunteers, and peers. As voiced by Participant 4:

"[T]hat's why we love Blue Sky Trust. Because it helps with us a lot.... when we came here, [they] said 'here's some [tissues], wipe your tears', because every time we cry. [They] comfort us, and they encourage me to make things, easier...[We] learn so many things, here. Depression, knitting, crochet (some participants laugh gently). Sometimes we knit so many scarves for... to raise our group, to going on, because we love it. We don't want to... to go down (noises of agreement). So we are fighting (pause) for it to raise up. That's what we are here for. Because we love it. It's ours. Nobody will fight for us. And we are strong." [P4]

The strength gained by one's involvement with BST and the need to 'fight' for both oneself and BST itself reflect the context in which social support services are provided. Outside of service provision, HIV-related stigma still negatively affects the lives of service users (2.3.3) and austerity measures continue to threaten the provision of HIV social support services in the UK (2.1.3). Participant 4's belief that "nobody will fight for us" is galvanised by these realities, reflecting an environment where 'fighting' is essential to survive and thrive. This ongoing fight was described as bonding the women, volunteers, and staff at BST together as a Family, with each person as an individual assisting in the communal push towards a possible positive future.

The Fighter theme blends and extends the conceptualisations of Family (a created community) and Friends (individually-led connections and acts), positioning the individual as a member of a broader community; one in which the individual 'I' works in coalition with others as a 'we' to affect their broader world and the worlds of others. This nuanced theme is further illuminated by two subthemes, reflecting specific aspects of this identity within the peer support journey in relation to valued aspects of peer support voiced by women living with HIV: supporting each other in the 'fight' and helping others.

4.5.4.1 Subtheme 3.1: *"But being all together, we've all got all this strength, that we give each other": The 'fight'*

Rather than a specific adversary or issue, the 'fight' more generally referred to the ongoing personal and shared journey towards a better life for each woman, whilst maintaining the strength for that forward momentum in oneself and each other. For Participant 7, previous negative experiences were related to her late diagnosis of HIV, which she began responding to after becoming involved with BST:

“I’ve made friends with everybody, and... it’s just helped me, y’know, understand—I didn’t want to know anything [about HIV when I was first diagnosed] (“mhmm” of agreement from another participant), I was ignorant, I think. All I could see was ending my life, because I didn’t think I was gunna be here today...they’ve given me five years now, and I’m going to prove them I’m going to go past those five years. (strong and positive “YES. YESSS!” from P4 – clapping from other participants).” [P7]

Women have the highest rates of late diagnoses of HIV (behind heterosexual men) in the UK (Public Health England, 2020), which has been shown to negatively impact both long-term health and reported QoL (Sophia Forum & Terrence Higgins Trust, 2018). P7’s utterance expresses how her personal ‘fight’ after her late diagnosis has been supported by her relationships with others, facilitated through her involvement with BST’s peer support services.

P7 further described how her involvement with peers in the group had helped foster feelings of strength:

“After a time, I realised that I wasn’t the only one; I wasn’t the only one feeling the pain, I wasn’t the only one that was suffering, the only one that was getting ill for different things and that, we all were the same, we all were suffering. But being all together, we’ve all got all this strength, that we give each other, I think, and it helps.” [P7]

While each woman’s fight is described as being specific to her own life, being able to share one’s journey and express similar experiences with peers supports everyone. Feelings of strength are created together by individuals connecting together as a group or community, that strength then feeding back to each member as they continue their individual journey. In this way the group progresses (‘fights’) towards a better life for all through the achievements of each woman individually.

4.5.4.2 Subtheme 3.2: “We should help others to live, to survive”: Helping others

In addition to considerations for their own lives and other group members, several participants also spoke of ‘fighting’ themes (e.g. strength, survival) in relation to their work as peer mentors, providing feedback to healthcare providers, or more generally volunteering at BST⁹⁸. In this way, individual strength becomes something to give as well as receive.

For P4, becoming a peer mentor was important as a way of helping others living with HIV, as she and others had been helped:

“Now I am learning to... take other, to student others peoples (sic), because I know where we come from was very difficult. But it, we should help others to live, to survive (noises of agreement from other participants). That’s why love this group.” [P4]

P4 illuminates how her life has changed for the better through her journey with peer support, highlighting the joy she has found in helping others ‘fight’ on their own journeys.

P2 spoke of her involvement with a medical programme in the region, where she would talk about her experiences of receiving medical treatment to help educate medical students on how to treat patients living with HIV:

“I’m doing... like, explain[ing], talk to the doctors... at the university that want to graduate, explain to them how to treat HIV patients... because most of them, they’re told that if you’re HIV... you know because of what the stigma [is, you know what] people are going through, [what] WE are going through.” [P2]

P2 explained that this utterance was related to her previous negative treatment at a hospital in the region. By supporting further training,

⁹⁸ Viewing contributions to one’s community as a form of ‘fighting’ for it resonates with similar values of peer support (as a form of community contribution) raised within BHIVA’s ‘Standards of Care’ (British HIV Association, 2018).

she hoped to help new healthcare providers develop a better understanding of how to properly treat those living with HIV.

Additionally, P6 described providing support to others as a general volunteer at BST, remarking that she hoped to add to the positive atmosphere of the organisation that so many participants noted as a key feature:

“I’m a bit of a volunteer kind of thing, kind of a-a, kind of a warm face, hopefully (laughs) when people come in.” [P6]

P6, similarly to P4, talked about contributing to BST as a volunteer to help sustain and recreate the positive experiences she had received as a service user.

Beyond wanting to help others as a means of providing peer support (P4), medical training (P2) and supporting BST’s activities (P6), participants also raised the importance of being further involved, ‘fighting’ for others, on a personal level. As a postgraduate student who had moved to the region for her education, P5 had initially joined the group at BST to find a local community to share her experiences with. She explained that:

“I knew that I had the capacity to live with my HIV, but without support (said passionately) from Blue Sky Trust and coming to meet with people who understand your situation and you also having the, the opportunity to give back to other people who are struggling to get to where you are (other group member “mmm”), it gives me that joy because Blue Sky Trust also give us the opportunity... to train us to become [peer] mentors who would also support other people in the... organisation who are... working towards standing on their feet. So it’s... an honourable thing for me to be here. Yeah.” [P5]

P5 expressed the personal value (the ‘honour’) of being able to contribute to positive developments in the lives of others by providing peer support. She also highlighted the ‘joy’ of being able to support others in their own journeys, echoing P4’s reflections presented earlier. Further to this, P5 describes the added value of peer support services at BST, not just in its ability to build the capacity of its

community, but also in fostering personal strength *through* that capacity building.

4.6 Reflections on Praxis

This study additionally provides insight into best practices for conducting community-based research with HIV social support providers. Conducting community-based work is a time-consuming and often messy process, requiring long lead-in times to allow for appropriate planning and discussion between stakeholders (Coughlin et al., 2017). Conducting any research within the HIV sector also involves time to build trusted relationships, and careful consideration of participant confidentiality. Using a community-based approach helped address these factors while remaining flexible to the needs and concerns of collaborating stakeholders, aligning this work to other community-based research in HIV (Bird et al., 2017).

This flexibility allowed this research to adapt and continue when faced with change and unexpected issues, largely caused by my own inexperience with the communities I was working with. Reflecting on this experience raises two critical learnings for conducting research in this space: (1) the design of study documentation; and (2) barriers to participation.

Study Documentation Design

In preparing an ethics application for this study I designed a range of study documentation (e.g. an information flyer, contact cards) for participants that would avoid sharing information unintentionally. Upon review, my collaborators at BST suggested that the wording be changed on the information flyers to explicitly mention wanting to hear from women living with HIV. When I responded to explain why I had left HIV-specific language out of the flyers, she replied to say that this was likely not to be an issue as most women would only

review study materials within the meeting room and then leave it there. This changed what I understood to be best ethical practice for informed consent documentation, and I reflected that I may have been too cautious in my study design and not considered the inherent confidentiality afforded by conducting research within a context of service provision. Moving forward I only designed my contact information cards without reference to HIV, designing all other study documentation to only be used in situ of research activities.

Barriers to Participation

This study originally included a questionnaire to capture participant demographic information and information on their use of a variety of digital technologies in daily life. Whilst this activity was envisioned to be a quick warm-up exercise prior to the FGD, several barriers to participation led to this task being largely abandoned in practice. I had not foreseen the language and physical accessibility barriers that conducting a written questionnaire would entail; these leading to several participants being unable to complete it. Similar accessibility barriers also affected the time needed to complete consent documentation prior to the FGD, as several participants required one-on-one support to read and complete the forms. This experience informed my choice to largely avoid or minimise the use of written responses as a form of data for this thesis work.

4.7 Summary

The focus of this exploratory study was purposefully broad to avoid limiting discussions and themes to existing concepts of peer support within HIV literature (Peterson et al., 2012). A nuanced understanding of peer support as a journey to strength, and the various aspects valued by participants (subcategorised as Family,

Friends, and Fighters) within it, was illuminated in the resultant themes by taking this approach.

Responses to SRQ1 (*What do women living with HIV value about peer support settings and services?*) informed subthemes that highlighted the valued and entwined aspects of peer support that assist service users on a personal journey towards strength; whether through receiving soothing services (Family), supporting self-management and embedded peer social support networks (Friends), or self-led acts of service for the collective community (Fighters). Previous research has shown similar realities of discrimination and isolation among women living with HIV in the UK (Sophia Forum & Terrence Higgins Trust, 2018), and the narrative of HIV peer support as a journey (Switzer et al., 2020). However, this is the first study to explore these themes conceptually specifically in relation to the design of effective peer support involving digital technologies: how the designed *form* of peer support services relates to these considerations.

Responses to SRQ2 (*How are digital technologies used in relation to the peer support group?*) provided additional insight. The picture of peer support painted by study participants shows an inclusive service that enables all its users to comfortably participate while remaining responsive and adaptable to individual need and growth.

This study offers some key insights addressing my first two PhD research questions. In response to RQ1⁹⁹, digital technology conceptualisation and use by women living with HIV is impacted by lived experiences, specifically around concerns about HIV information sharing. Experiences of discrimination and rejection

⁹⁹ RQ1: How does lived experience impact on the conceptualisation and use of digital technologies by women living with HIV in the UK?

related to HIV stigmatisation make the sharing of HIV information a negative and potentially dangerous action for women living with HIV, which may position any form of connection to that information as a risk. This includes information shared through digital communications, such as inclusion in a group text message, a digital message's content, or connections visible to other on social media platforms.

Despite this risk, digital technologies are also commonly available and used within the women's daily lives, especially mobile phones. In this way, *the risk of using digital technologies can be understood to be more connected to the risks of HIV stigmatisation rather than the technologies themselves*. This aligns with other studies involving digital interventions among women living with HIV; these have found that interest in using digital interventions was more related to the content and connections that digital technologies supported, rather than the technologies themselves (Marhefka et al., 2019). Such findings also echo previous HCI research that found the use context held more importance to the effectiveness of a digital intervention for women living with HIV than the technology itself (Natarajan & Parikh, 2013). This highly context-specific nature of digital technology use was echoed by participants at the BST; they described how willingness to use digital technology with peers changed over the course of their peer support journeys: from not wanting any connection with others at first introduction (Family), when concerns about HIV stigmatisation may be high, to a point when trust and relationships are built and women feel comfortable with establishing connections with peers (Friends; e.g., texting a peer in the hospital), often accompanied with a more active role within the community (Fighter).

BST respond to these changes within individual clients through their inclusive and responsive approach to service provision using digital technologies, offering insight in response to RQ2¹⁰⁰. Their use of text messaging allowed important group information to be communicated to service users confidentially and meaningfully, extending the comforting and supportive aspects of peer support beyond meetings alone. They chose to send texts to all members of the group individually, thereby protecting individual confidentiality and allowing each recipient to manage the message appropriately for themselves, whilst also reinforcing that recipients were not alone in their experiences. The content of messages was carefully considered, using a warm and familiar tone of voice to provide a sense of comfort and connection, similar to that within group meetings. Sending text messages individually also allowed service providers to adapt text messages in response to unique confidentiality concerns, enhancing the inclusivity of the digital service by making it suitable for all users. Using text messaging for service provision provided an example of how self-led digital interactions involving HIV could work, potentially inspiring service users to utilise messaging within their own embedded peer support networks and/or peer support provision for others.

Of equal importance was which digital technologies BST chose not to use for service provision. Given service user concerns about confidentiality, digital technologies that could group or otherwise connect users were not used. This included social media platforms (such as Facebook) or group chats (such as those commonly used in WhatsApp). While BST does have Facebook and Twitter accounts, these are primarily used for public announcements, events, and fundraising activities instead of service provision. The use of

¹⁰⁰ RQ2: How are digital tools and services designed and used within HIV social support services for women living with HIV in the UK?

acceptable tools and services readily available to service users (e.g., mobile phones) further promoted inclusivity and accessibility, allowing all service users to easily access digital components of service provision.

This first empirical study informed my foundational understanding of the form and framing of peer support services for women living with HIV in relation to digital technologies through the experiences of service users. I gained insight into how the experiences of women living with HIV affect their digital technology use (RQ1) and how digital technologies are used within service provision in response (RQ2). In the next chapter, I report on further work exploring how digital HIV social support interventions are themselves designed; this work was conducted through an internship project for the National AIDS Trust (NAT). In Chapter 5, I set out a reflective account of my experiences as a design practitioner assisting in the co-creation of a novel online tool in collaboration with NAT and a digital agency. Through this I shed further light, from the perspective of being embedded in a service design project, on how digital interventions are developed by HIV service providers and how designer-researchers may support these co-creative projects.

5 Reflections on the Collaborative Development of ‘Looped in’: a Digital Tool for Informational HIV Social Support

5.1 Introduction

It is arguably important to understand how digital tools and services are developed in the field in order to pragmatically align design activities. This insight informs where design research may be of use within development processes, equipping designer-researchers with the knowledge to apply design praxes meaningfully and collaboratively when working with service providers.

This chapter does not report on a formal study; rather it is a reflective account (Sengers et al., 2005) of my experience working in the HIV sector as an ‘expert’ designer (Manzini, 2015). It provides insights into how this experience shaped my methods for the doctoral studies that followed, and the development of my thesis. In this account, I also formulate a response to my second PhD research question (RQ2)¹⁰¹, analytically reflecting on the process of developing a digital tool for HIV informational social support¹⁰². In this chapter, I write through the lens of my personal experience as a design practitioner

¹⁰¹ RQ2: How are digital tools and services designed and used within HIV social support services for women living with HIV in the UK?

¹⁰² Informational social support, such as advice or knowledge sharing, is one of the three forms that social support can take; the others being instrumental support (such as providing transport) and emotional support (Cohen et al., 2000; Huh et al., 2014).

during a six-month internship with the National AIDS Trust (NAT)¹⁰³. I reflect on the personal-professional insight that I gained working within a design team, to shed light on *how* digital tools and services are designed within HIV social support services. In this account, I also critically reflect upon how my personal experience informed how I set out to address my third PhD research question (RQ3)¹⁰⁴, and how it helped me build a tacit understanding of how design praxes involving Digital Health tools and services within the context of HIV might be applied usefully within collaborative projects.

Between August 2018 to March 2019¹⁰⁵, I worked at NAT as a Community Digital Project Intern (project intern), in the capacity of design researcher and product manager for NAT working with a digital agency to collaboratively develop 'Looped in'. 'Looped in' is an online tool that allows users¹⁰⁶ to create curated information sets that they may share with others via a unique URL link and/or downloadable PDF. This experience allowed me to gain real world, sensitising experience of design work within a team at an HIV organisation developing a digital social support tool. As a project intern, I managed communications between key stakeholders connected to the project; coordinated project tasks with the digital agency; and led several design research activities with key NAT stakeholders and community representatives to support the overall development of the digital tool.

¹⁰³ <https://www.nat.org.uk/>

¹⁰⁴ RQ3: What approaches can inform design praxes involving Digital Health tools and services within stigmatised health contexts?

¹⁰⁵ This included two separate periods of employment (August 2018-December 2018 and January 2019 to March 2019), as my contract was extended beyond its initial four months so that I could provide additional support during the building of the digital tool.

¹⁰⁶ The user population for this project included, but was not limited to, women living with HIV.

Reflective insights from this internship experience, relevant to my doctoral work, are documented through the presentation of three Reflective Design vignettes (Sengers et al., 2005). I present short reflective accounts inspired by Design Ethnography (Salvador et al., 1999) on key points in my experience of the development process, devised to illuminate how instances of internship experience connect to an 'expert' design praxis. I explore how collaborators defined what was made together through these unfolding reflections. Using Wayne Chung's 'Design Praxis Matrix' (Chung, 2019) as an analytic tool, I identify (in) tangible activities and outputs within these vignettes to support my reflective analyses of key moments within the development process.

By critically reflecting on my observations and experiences as a design practitioner developing 'Looped In', I provide insight into how digital tools are developed by HIV social support providers, identifying areas in which 'expert' design praxes may be meaningfully positioned to support responsible digital innovation. I explore how the collaborative unfolding of this internship offered transferable insights that guided my future design praxis. I was further inspired by previous Service Design research on the role of the designer within the third sector (e.g., Warwick & Djaelani, 2016; Warwick & Young, 2016) and interdisciplinary design projects in the context of HIV (Wizinsky, 2019). Developing digital tools and services collaboratively is complicated, as is developing interventions within the context of HIV social support services. In reflecting on my own experiences, I explore how a design praxis unfolded in a commercial development process, and explicate the lessons learned.

1.1.1 Background

NAT was founded as a charity in 1987 to fight for the rights of people living with and affected by HIV in the UK. Their current work largely

focuses on providing advocacy support to shape national policy involving HIV. NAT releases regular policy reports, guides, and annual reviews on issues affecting the lives of people living with HIV in the UK. Most recently this has included successful legal efforts to overturn the NHS England decision not to commission PrEP, a drug that prevents HIV acquisition through sex (The National AIDS Trust, 2016a). NAT is unique as an HIV charity as they do not provide social support services (such as peer support) directly; instead providing informational support (Cohen et al., 2000; Huh et al., 2014) through research and advocacy on a national scale.

I was informed of a job posting by the National AIDS Trust (NAT) for a project intern while working with BST during my first study (4.0). The internship involved assisting in the development of what became 'Looped in', informed by NAT's national community, which NAT had received external funding for in collaboration with a digital agency.

I worked as project intern at NAT for six months between August 2018 and March 2019, either from home or within NAT's offices in London for a few days each week. During this time my responsibilities included supporting the conceptual development of the digital tool (i.e., what it would be); conducting and analysing design research activities to inform the development and design of the tool; and working as a product manager to maintain communications between NAT, the partnering digital agency, and the representative from the funding body. A contract defining my independent ownership over some design and research activities was also drafted between NAT and myself (see Appendix D.1.1). This contract was created to allow me to report some aspects of my internship experience, such as an account of my professional practice and personal insights, within my doctoral work.

Representatives from NAT have read and approved this chapter in keeping with this agreement.

5.2 Writing Reflective Accounts

As I present a reflective account rather than a formal study, I will first outline how I approached reporting on my experience and related ethical considerations.

1.1.2 Reporting on my Internship Experiences

My personal reflections focus specifically on *how* my involvement in key design activities within the development process of ‘Looped in’ relate to a collaborative design praxis. The reflective vignettes illuminate my role in the project and its conceptual development through (in)tangible activities and outputs during the collaborative development process.

Design Ethnography uses ethnographic methods to examine how everyday patterns relate to the conception, development, and design of outputs (Salvador et al., 1999). I was inspired by Design Ethnography to organise and review my (1) field notes, (2) design materials, and (3) design outputs to deepen my understanding of the project development, and my practitioner position within it. Materials were chronologically organised to reflect the development process, before being reviewed in full. *Instances* of design activity were then chosen based on their impact to the conceptual and pragmatic development of the NAT project across the timeline (see Fig. 10 below).



Figure 10: NAT project timeline with the dates of key design activities noted.

Activities noted along the top of the timeline were selected for their impact on project development.

I then began writing my reflective account of these selected instances using a Reflective Design approach (Sengers et al., 2005). Reflective Design uses critical reflection to “[bring] unconscious aspects of experience to conscious awareness, thereby making them available for conscious choice,” supporting ongoing critical reflection about the relationship between technology and human life (ibid., p.50). I used Chung’s (2019) Design Praxis Matrix to support reflection on key design activities within these instances in relation to my experiences as a design practitioner.

The Design Praxis Matrix (see Fig. 11 below) illustrates how design methods relate to each other within a dynamic design process, dividing methods along two axes (tangible/intangible and outputs/activities), forming four quadrants (Doing, Framing, Defining, and Making) (Carnegie Mellon Design, 2018). Most straightforwardly, intangible things are ideas or knowledge, and tangible things are stuff—you can hold something intangible in your mind and something tangible in your hands. Design outputs are created things, whereas design activities are ways of creating things. I use Chung’s Design

Praxis Matrix to methodically reflect on my internship experience and define key moments in relation to how they involve (in)tangible components. I focus specifically on how the abstract knowledge (*intangible*) of HIV service provision (i.e., contextual understanding of the service user) informed the *tangible* designed form of what was made. For clarity, I note where ‘abstract knowledge’ and ‘tangible designed form’ are mapped to the Design Praxis Matrix below in pink text (see Fig. 11) to highlight where they are located within the Matrix. This practice illuminated insight because I could explore how design activities were involved in design praxes, how these design praxes unfolded in action, and how critical reflection highlighted previously unconscious aspects of my experiences.

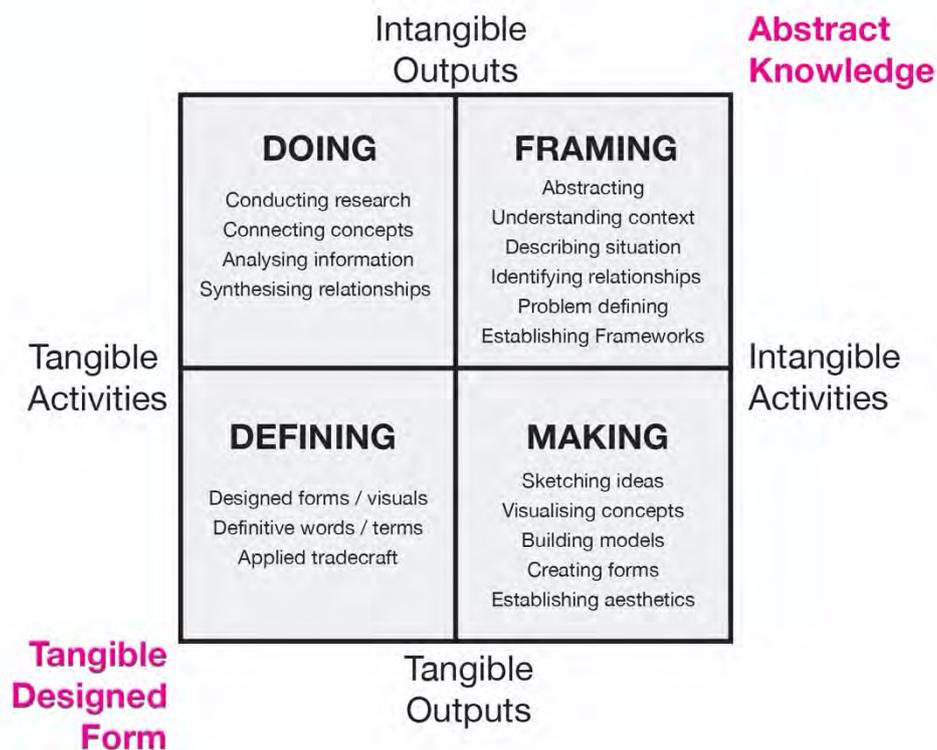


Figure 11: The 'Design Praxis Matrix' created by Wayne C. Chung (2019). Pink text added by the Author to define 'Abstract Knowledge' and 'Tangible Designed Form' in relation to this Matrix. Image credit: Author after (Chung, 2019).

1.1.3 Ethical Considerations

I present three vignettes reflecting upon my experiences as a design practitioner, and critically considering how key instances within the technical development process affected the design process.

Because of my positioning as a design practitioner within a commercial project¹⁰⁷, independent ownership of design research activities and materials was agreed upon with NAT (see Appendix D.1.1) allowing me to use my time within the role to inform my doctoral studies whilst fulfilling my contractual duties as an employee.

Whilst the account of work in this chapter represents my own experiences and analyses as a design practitioner on the project, this has been reviewed by representatives at NAT prior to including it in this thesis. This review was carried out both as a form of fact-checking my accounts, and to support my methodological commitments to Critical Ethics (3.2.4). My account will be published in the public domain by way of this thesis, making it ethically imperative that it would not negatively affect the collaborators involved. The focus of the report is to show how the design process unfolded, not how individual collaborators shaped it; the focus is on the process, not the people involved.

The vignettes do not serve as a 'roadkill' analysis of the messiness inherent to any collaborative or co-creative project. Instead, I explore how these complexities affect the design of emergent artefacts within complex contexts. The review by collaborators at NAT helped avoid potential misrepresentation of activities and provided space for additional ethical concerns to be voiced and addressed. This was key to supporting my commitment to Critical Ethics (3.2.4) and my

¹⁰⁷ The intellectual property (IP) of 'Looped in' is shared between NAT and the partnering digital agency.

positioning within Fourth Wave HCI (Frauenberger, 2019) – given the potential harms of reporting within sensitive design spaces.

5.3 Reflective Vignettes

I combine my experiential accounts and critical reflections on key design activities within the following reflective vignettes, inspired by the ethnographic format of blending analysis and account together. These vignettes focus on three distinct stages within the product development process (initial concept definition, prototype testing, and final product development), and their associated design activities (comprising an internal report, a user testing workshop, and illustration prototypes), respectively. Vignettes are presented chronologically to reflect the progression through the project activities. I use both third- and first-person language to reflect my dual role as both observational narrator and active participant in the unfolding design process and acts of reflection.

1.1.4 Reflective Vignette 1: Framing the Project

1.1.4.1 The Internal Research Report

One of my first tasks on the project was to help define the conceptual focus of the digital tool being developed, working with NAT to clarify what we were making and why. The initial project concept had been changed due to concerns about the technical scope of the project¹⁰⁸; In response, NAT and the digital agency were now considering a digital service that could email HIV information anonymously. Shortly after I started working at NAT, the partnering digital agency led a workshop¹⁰⁹ at NAT's office to help define what aspects of this

¹⁰⁸ The project had initially been focused on creating a chatbot to provide informational support. As the project was being funded in a way that respected iterative development processes, switching the focus of the digital project after funding had been awarded was not an issue.

¹⁰⁹ This workshop was conducted on 9 August 2018. It included various generative post-it activities (on user access routes, potential content to include, and possible

concept needed further definition from NAT (see Fig. 12 below). The workshop was run with a small group of key stakeholders at NAT, including myself, and the project manager from the digital agency. The designer originally affiliated with the project at the digital agency would soon be leaving for another job, being replaced by another designer from within the company soon after the workshop.

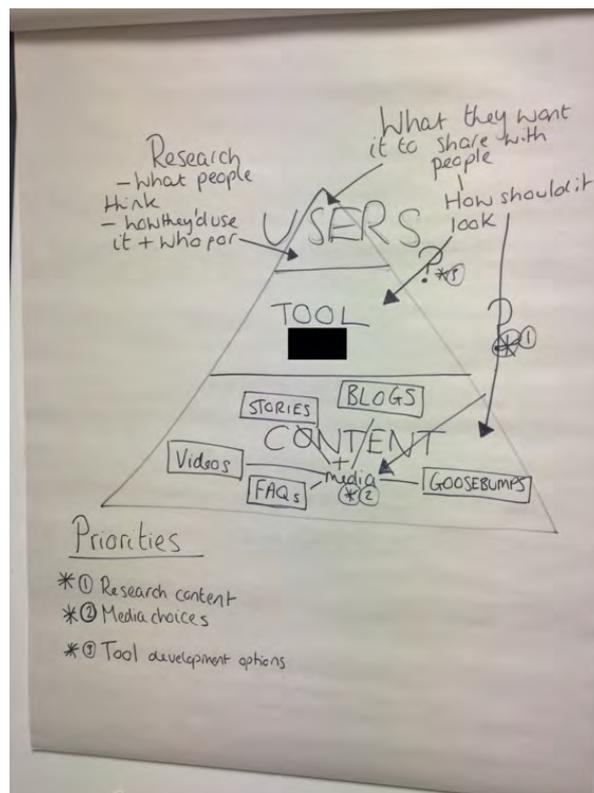


Figure 12: A sketch of what needed to be further defined within the NAT-led project, created during the workshop led by the digital agency's project manager on 9 August 2018.

Image credit: Author.

At the workshop it was clarified that NAT needed to further define (1) the user population for the digital tool, (2) why they would want to use a digital tool for informational support, and (3) the content

use scenarios) as well as analytic mapping of potential content recipients to identify key audiences.

needed to support them in that use. NAT staff members had previously conducted user research on the needs and concerns of potential users living with HIV in relation to a digital information tool, which would be able to inform the identified priority areas raised in this workshop. A former NAT staff member had conducted interviews [n=6] and questionnaires [n=14] with people living with HIV across the UK to inform the design of this tool. However, these data had not been formally analysed due to other commitments and staff turnover. I expressed interest in analysing these data to refine the conceptual focus of the project, and was granted access to the available anonymised notes, transcripts, and forms.

I inductively coded these data by hand, using Thematic Analysis (Braun & Clarke, 2006) to draw out design features and potential use contexts voiced by participants. I then sorted these codes into six thematic categories to frame how participant feedback related to different design considerations:

- **Functionality:** features that would need to be coded into the structure of a digital tool;
- **Content:** the kinds of informational support participants voiced as desirable;
- **Design:** notes on the desired aesthetic presentation (front-end design) of the visual tool
- **Use in Real Life:** insights into what context(s) participants envisioned using the tool;
- **Communication:** considerations for the tone of content and potential audience considerations; and
- **Concerns and Fears:** specific considerations for the tool as an information support tool about HIV that would affect its design.

I then used this thematic structure to write an internal report for stakeholders within NAT and the partnering digital agency.

The report provided an overview of the themes and codes with comments on my analysis, their connection to the design of a digital tool, and key participant quotes. It also included a brief project introduction to summarise NAT's goals for the digital tool (*"A tool to empower people living with HIV in the UK to transform the way others respond to HIV"*) and a glossary of key terms and acronyms common to the HIV sector used within the report. After being reviewed by internal stakeholder at NAT, it was distributed to the wider digital project team on 6 September 2018, and presented to internal project stakeholders at NAT the following week.

Using the report as a reflective tool in discussions with NAT stakeholders proved useful in refining the conceptual focus of the project. Research insights informed the decision to move away from a tool that sent anonymous emails (which might arouse concern and suspicion) to an informational tool that could allow users to customise sets of information for specific use contexts¹¹⁰. Stakeholders within NAT valued that this new focus was informed by community feedback and interests, and were confident in moving forward with this conceptual focus. However, at the time I submitted the report, the digital agency's focus was on overall project planning and architecture. I reflected that the internal report didn't describe how insights could be used to inform the development of the tool at this point in the process, making the report less applicable to their needs in comparison to NAT.

¹¹⁰ This new approach framing the customisable informational support tool as a proactive resource made for people living with HIV, designed to lessen the 'educator's fatigue' of supporting others in understanding and supporting them; similar to information packages available for those supporting people living with other chronic health conditions.

1.1.4.2 Reflections on Praxis

When considered with the Design Praxis Matrix, the creation and dissemination of the internal research report represents an attempt to understand the design context (Framing) of the digital tool through analysis of research data (Doing). This was done to better define the conceptual focus of the digital tool and thereby its content and potential form (Defining) (see Fig. 13 below).

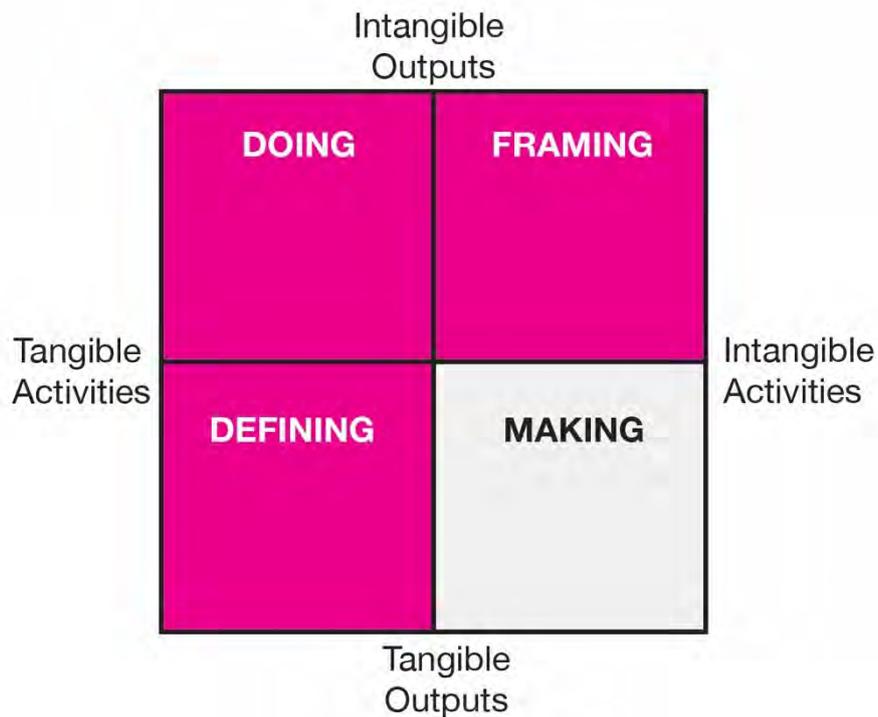


Figure 13: The creation of the internal report mapped onto the Design Praxis Matrix (in pink). Image credit: Author after (Chung, 2019).

Whilst this contextual understanding was valued and utilised by collaborators within NAT to support project framing and definition, it lacked utility for collaborators within the partnering digital agency. Upon reflection, I believe there could be a few reasons for this: (1) how Framing (Chung, 2019) was used; (2) available staff resource due to multiple responsibilities; and (3) the timing of the report's release within the project development timeline.

I had hoped that the written report would serve as useful reference tool for any collaborator, however, upon reflection, I realise that it mainly worked to contextualise understanding in relation to the user. Understanding the needs of users was the responsibility of NAT as the service provider involved in the project, so it logically follows that the report was more useful for NAT. As a designer immersed in how context relates to digital tools and services, I had overlooked that within this commercial project, intangible outputs (such as Framing) were the domain of NAT and not the digital agency.

Secondly, committing resource for collaborators to engage in Framing aspects of the project was limited for several reasons. The focus of the project changed after funding had been awarded, at which point several staff involved with the initial project's concept were not available. This meant a new shared Framing needed to be established, however, committing staff resource to this was difficult given the multiple concurrent responsibilities of both collaborators. Whilst I had been hired by NAT to address this issue in a role dedicated to the project, there was no such person within the digital agency. This meant that even though I was able to dedicate time to understand and define the new conceptual Framing of the tool (key for NAT's activities on the project), at this point in the project collaborators at the digital agency would need to focus their time on Defining and Making the digital prototypes and final tool. The utility of the internal report for the digital agency may have been greater if it focused on clearly defined design parameters (e.g. requirements) rather than conceptual Framing (e.g. to inform Making within a design praxis).

Lastly, insights from the report may have been useful to digital agency collaborators if I had provided them at specific points within

the project's development. Development stages were divided into a series of 'sprints', or dedicated timeframes in which a series of defined tasks would be completed. The internal report was disseminated at earliest availability; however, the agency would not be focusing on the project until later. Developing the report more specifically, perhaps as a series of small reports dedicated to the tasks involved with a given sprint, and then delivering it at the start of a sprint may have better applied report insight to specific tasks.

The limitations of the internal report to support a collaborative Framing of the project helped me learn more about how this project used design praxes. The collaborators used different approaches to understand what they were making and why: NAT valuing intangible outputs (Doing and Framing) to inform what they would do, and the digital agency focusing on tangible outputs (Making and Defining) to guide their work. This was informed by the division of responsibilities within the project: NAT team members knowing what to make, and the agency making it. As the internal report was developed to support an intangible, Framing-led praxis it seemed more useful to NAT staff than the digital agency. In hindsight the report should have been adapted to serve the needs of the design agency, defining tangible forms rather than abstract contexts alone, and delivered at an appropriate timeframe to better support the intangible aspects of their Making design activities. This insight informed my approach to designing collaborative activities and outputs for the remainder of the project.

1.1.5 Reflective Vignette 2: Reviewing the Prototype

1.1.5.1 Community Review Workshop

Once a new project concept had been established, it was important to explore it with potential users living with HIV to refine our idea and inform its final development. This served the interests of both NAT

and the digital agency, aligning the project closer to a community-based approach and facilitating early prototype evaluation within the tool's iterative development.

I worked closely with a member of NAT staff (herein referred to as the 'NAT coordinator') to organise a user testing and feedback workshop with an HIV social support organisation in the North West of England, who recruited participants from their client base. We arranged for this workshop to be preceded and followed by separate meetings at the offices of the digital agency, which was local to the workshop venue. This scheduling was chosen to minimise travel costs and allow for collaborative team members to prepare and debrief the workshop's events together.

On the morning of November 8, 2018, the NAT coordinator and I travelled to the North West, meeting with the project manager and senior UX designer from the digital agency at their offices. We created an itinerary for the workshop and prepared our respective workshop materials. We began the session with all participants in a large group for introductions, before dividing them into two smaller groups, allowing for various research activities to be conducted with all participants within the time available. The digital agency pair ran prototype evaluation activities with one small group, showing the current prototype on a smartphone; concurrently, the NAT coordinator and myself conducted small qualitative research activities with the other group to discuss the tool's concept, content, and potential use case scenarios (see 'Scenario Comics' excerpt and Fig. 13-16 below). These activities lasted 30 minutes before the small groups were switched. After another 30 minutes there was a short break before reconvening all participants for a group discussion on the workshop experience.

Scenario Comics

Scenario comics were used during the community workshop to help us explore how the digital tool could be used in the everyday lives of potential users. I created four scenario comics (Fig. 14-17) with the NAT coordinator, illustrating how features of the digital tool could be used in different contexts. We chose to use scenario-based communication, an established design research approach within the HCI field (Carroll, 2000), to illustrate potential applications and features of the digital platform. The use of scenarios allowed various features of the platform to be contextualised in familiar ways, inviting participants to consider how these scenarios of interaction related to their daily lives. Drawing on the medium of sequential art, illustrations were added to provide further explanation and to improve comprehension for a broad range of participants (Buxton, 2007), who may have various levels of technology experience and confidence. Visual storyboards have been shown to successfully foster dialogue with broad audiences through their perceived simplicity and accessibility as 'rich pictures' (Durrant et al., 2018).

The four scenario comics are shown below, illustrating four potential use scenarios informed by insights from the internal report: (1) creating a custom PDF to support in-person conversations with a family member following a conversation about living with HIV (Fig. 14); (2) curating specific information on legal rights and sharing it via URL with friends in a group text after being discriminated against at a job interview (Fig. 15); (3) curating and sharing HIV information via URL with a match from an online dating website over WhatsApp (Fig. 16); and (4) emailing curated HIV information to a community leader to address an issue within the community group's online platform (Fig. 17).

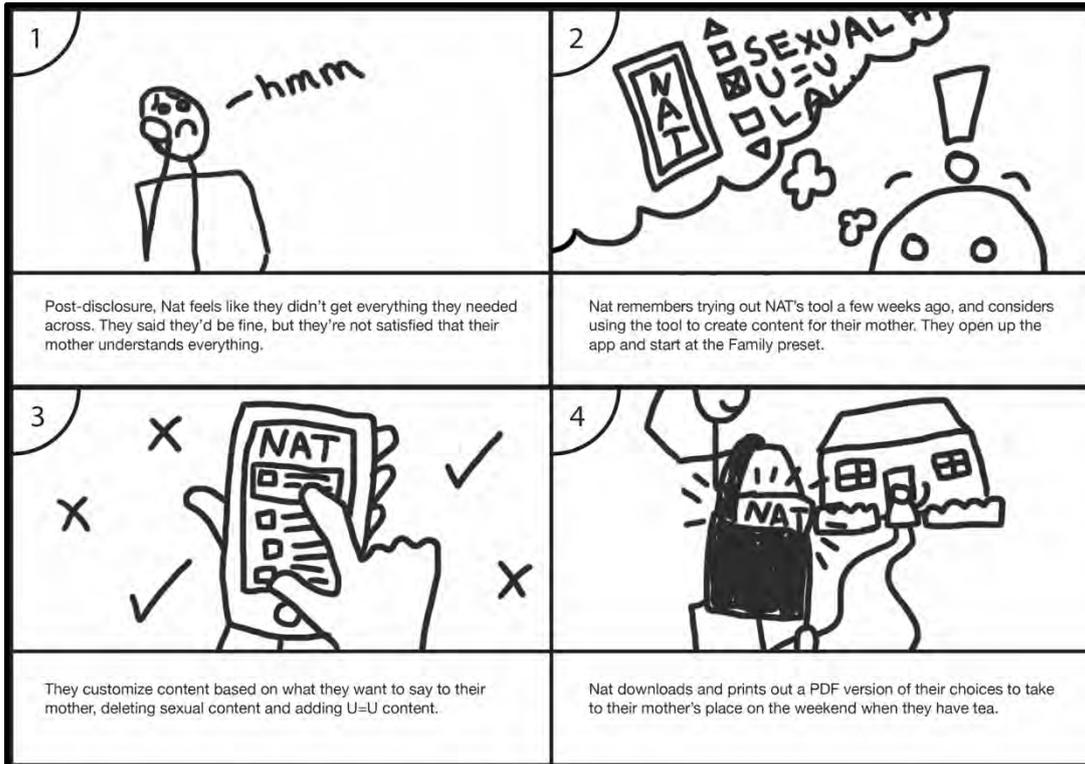


Figure 14: *Scenario Comic 1: Creating a custom PDF to support in-person conversations with family following a conversation about living with HIV.* Image credit: Author.



Figure 15: *Scenario Comic 2: Curating specific information on legal rights and sharing it via URL with friends in a group text after being discriminated against at a job interview.* Image credit: Author.



Figure 16: Scenario Comic 3: Curating and sharing HIV information via URL with a match from an online dating website over WhatsApp. Image credit: Author.



Figure 17: Scenario Comic 4: Emailing curated HIV information to a community leader to address an issue within the community group's online platform. Image credit: Author.

The workshop ran over a two-hour period, with nine participants attending and consenting to being audio-recorded¹¹¹. Participants were recruited by the hosting HIV community support organisation using purposive sampling, to reflect the gender, age, and ethnic diversity of its user base. Each participant was given a £10 Amazon voucher for their time. The participants responded positively to all workshop activities and the concept for the digital tool, many of them saying that they would find it useful. Prior to leaving the workshop venue, I talked with the NAT coordinator and the representatives from the digital agency; we unanimously agreed that the evening had been a very positive experience.

On the following day, I returned with the NAT coordinator to the digital agency's offices to discuss the workshop, and to complete some wireframing activities led by the agency. We were joined by the senior NAT staff member (i.e., my manager) responsible for the project. The first hour was spent discussing how the workshop had worked. The NAT coordinator and I were happy to report that the concept had been well received by participants, who had considered the case scenarios to be realistic and accurate. The group discussion at the end of the evening had also been productive, with participants providing feedback on specific considerations about how the digital tool and its content should be designed, and offering suggestions about how the overall digital format could be used in the future¹¹². The collaborators from the digital agency also gave positive feedback and voiced that they had enjoyed the opportunity to test a prototype

¹¹¹ Consent forms were provided for all participants to allow for audio recordings of group discussions and the collection of worksheet responses. This data would be collected, stored, and owned by NAT for use in evaluating studies and other reporting publications.

¹¹² Several participants had raised that the customisable format of the digital tool would be useful for specific issues or audiences (e.g. a specific website for talking about HIV with children). The scope of this project was specifically focused on an adult audience.

with prospective users first-hand. They reported that their user testing sessions had given them good insight into edits they would make in the next iteration of the digital tool. Overall, the workshop was viewed as a useful event that had provided valuable user insight for all collaborators.

There was one exchange during this discussion that stood out to me. One of the collaborators noted that the participants had strongly voiced that they did not want to 'log in' (i.e., have a personal account with a password) to use the website and prepare their customised data sets, as they felt they had too many digital accounts. This feedback prompted the research team to seek to remove accounts from the digital system moving forward. This surprised me, as I had raised this issue with the same group a month earlier, prompted by my experiences in other research projects and the internal report data. While I was happy that this idea would be adopted for the project, I reflected that participant's feedback had more clearly communicated this idea because it had applied contextual insight to a specific feature of the digital platform.

1.1.5.2 Reflections on Praxis

The community review workshop (including its preparation and subsequent debriefing) worked as a design praxis led by tangible outputs: tangible things were 'made' (e.g. prototypes and worksheets) in order to 'do' design research that would 'define' what form the final digital tool should take (see Fig. 18). Whilst some of NAT's workshop activities (e.g. scenario comics) contributed to better contextual understanding (Framing) of how the tool might be used, these were led by tangible outputs (comics) rather than abstract discussions.

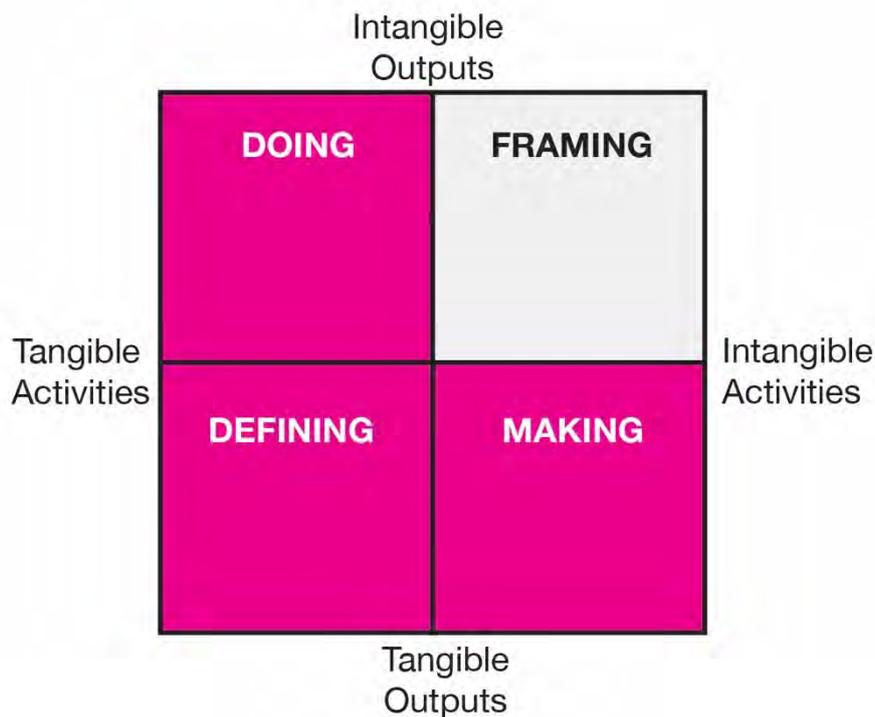


Figure 18: The community review workshop activities mapped onto the Design Praxis Matrix (in pink). Image credit: Author after (Chung, 2019).

All collaborators found the experience of conducting the workshop with community participants valuable, albeit for slightly different reasons. As NAT stakeholders, the workshop served as a sense-checking exercise, validating our conceptual approach and providing insight into how the digital tool could be better aligned to the needs and values of potential users living with HIV. For the digital agency, it was reported to be a useful opportunity to gain direct feedback from users on the form and use of the digital tool they were designing.

Whilst the concerns and interests raised about the digital tool in the workshop were common topics in the HIV sector¹¹³, this was likely the first time that staff at the digital agency had been directly faced with these issues in the context of their work. Collaborators from the

¹¹³ For example, privacy concerns about others seeing the user accessing HIV information.

digital agency expressed that it was unusual for them to conduct work face-to-face with users, as they most often worked with organisational stakeholders when developing digital products. Using familiar tangible outputs, such as the interactive prototype, as an entry point to these issues may have helped support their praxis within this unfamiliar space, keeping contextual use insights (e.g., users frustrated by having too many log-ins) specific to tangible features of prototype (e.g., using cookies to avoid using log-ins).

The use of a tangible prototype framed user responses as specific feedback for the development project, as participants provided contextual feedback specific to what they were shown. Contextual insights were linked to tangible things, for example: I don't want to have to log in (the tangible application) because I have too many accounts to remember details for that I often forget them (contextual framing). This direct commentary on design features avoided abstraction, keeping discussions about the contextual use (Framing) of the digital tool specific to tangible outputs. Reflecting on this, I believe this may be why the contextual reasons raised about using accounts within the digital tool were better translated through workshop activities – using user accounts being understood as a bad idea because the user said they were disinterested in using them when shown, not because another approach might be better¹⁴. This kept changes to conceptual framing linked to objective criteria rather than abstract knowledge, as contextual considerations were directly applied to tangible outputs.

¹⁴ On a theoretical note, it is also interesting to reflect on how the embodied nature of the workshop activities may have affected meaning making for workshop facilitators. Both Stein and Levinas's theories are based on one's accountability to the other once *faced* by them. The embodied act of physically facing prospective users, being accountable to them, may have more meaningfully communicated contextual understanding of how the digital tool would be used than any report.

The success of the workshop activities illustrated the importance of using tangible outputs within project development: defining the final form of the project through contextualised feedback on tangible representations of things. Using tangible artefacts to express our intangible framing of the project, our understanding of what would work and why, allowed a shared understanding to develop for everyone. Whilst the time and resource required to arrange the event made it unfeasible for a repetition within the development process, it was an invaluable activity that informed the final design of the digital tool. This insight guided my use of tangible outputs as a means to elicit defined criteria for the final digital tool.

1.1.6 Reflective Vignette 3: Making the Digital Product

1.1.6.1 Looped in

At this stage in the development process, we had decided upon the final concept and name of the digital tool: 'Looped in'. As the following reflective vignette focuses on the production of illustrations for 'Looped in', I will now provide a brief description of the final digital product to help contextualise this key design activity.

'Looped in' is an online tool (a website) that allows users to create curated sets of HIV information that may then be downloaded as a PDF and/or shared as a custom website via a unique URL link. This name was chosen by NAT as a play on words ('looping in' someone to a conversation; keeping them 'in the loop') and in reference to the 'looped' red ribbon, an iconic symbol of HIV activism and awareness.

To use 'Looped in', a user first chooses their relationship to the recipient of the curated information (e.g., family, sexual partner, etc.). They then 'save' specific content¹¹⁵ from various topic categories

¹¹⁵ The 'Looped in' website uses cookies, rather than individual accounts, to remember what content has been selected. This is explained within an initial pop-

(e.g., Living with HIV Today, How HIV works, etc.). A user's 'saved' content can then be reviewed and organised from the 'My Saved Info' button along the navigation bar of the website, showing users how their curated sets will appear once finalised. Once the user is happy with their curation they may generate a unique URL link, download a PDF, or directly share the URL over several social media platforms (see Fig. 19).

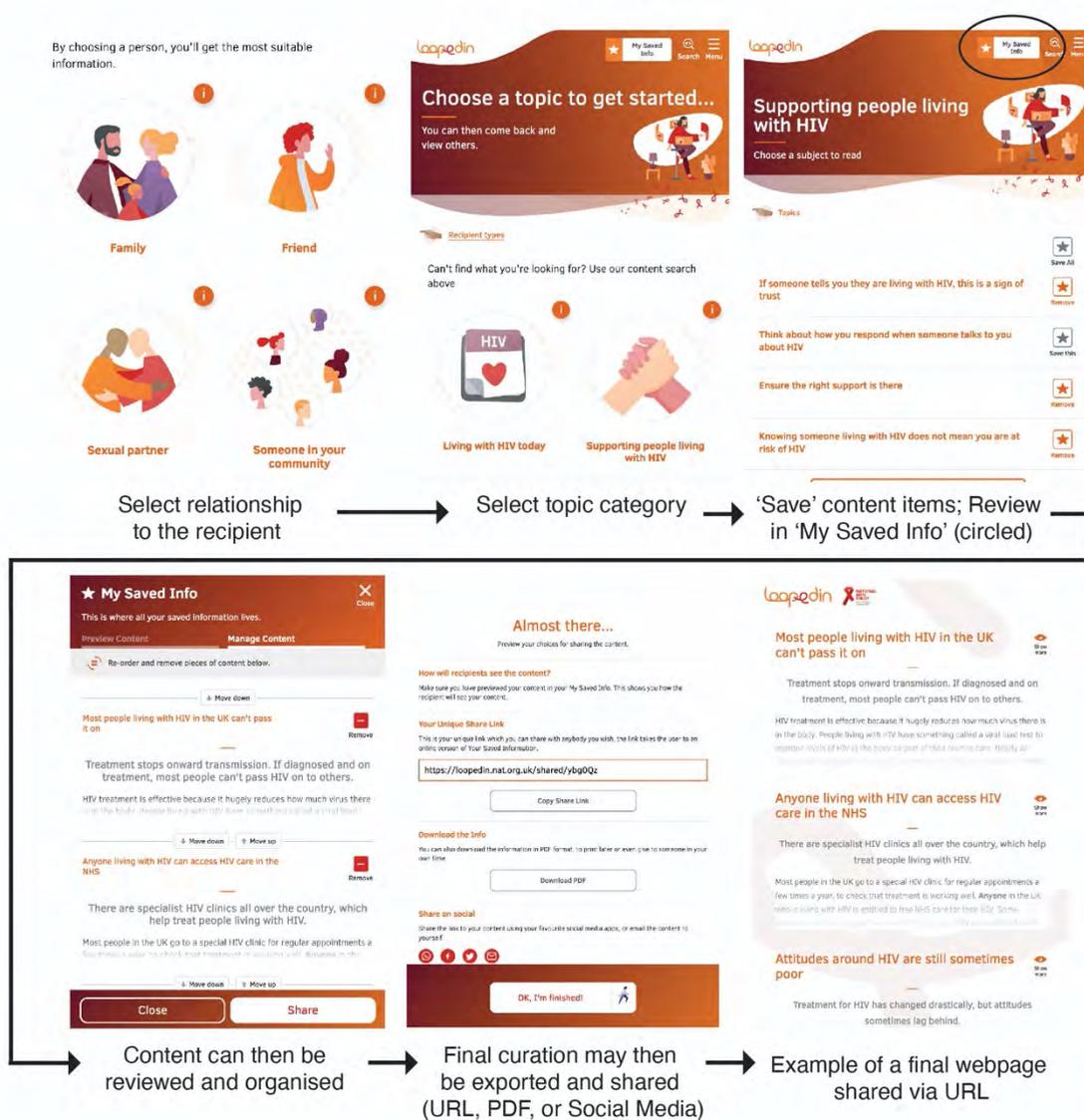


Figure 19: The process of selecting, curating, and sharing content on 'Looped in'.

Image by Author.

up window asking for permission to use cookies, appearing when a user first visits the website.

As a curation-focused platform, 'Looped in' required a large quantity of written and visual content to be produced, including HIV information blurbs, illustrations, and icons. NAT produced the written content while the digital agency produced the visual and coded aspects of the platform. In the following vignette, I reflect on how a series of illustration prototypes helped support the development of illustrations for the website.

1.1.6.2 Illustration Prototypes

The team members' focus shifted from defining what the digital product would be, to what content it would include, during the final production phases. The visual design of the digital tool was identified as an important use factor by potential users. Users mainly related this to how information about HIV would be perceived by recipients, with visual presentation elements (such as logos and illustrations) voiced as being important in communicating information in a friendly way and highlighting the trustworthiness of the source. In other words, designing the digital tool to be visually appealing and stylistically in line with NAT's branding was critical to its effectiveness.

The inclusion of engaging visuals and media was therefore a key deliverable of the project. Whilst the written content of the digital tool was the responsibility of NAT, visual content was created by the digital agency's web designers and in-house illustrator. The project team members requested various illustrations to be made that depicted: (1) people engaging with the digital tool (illustrations of 'people'); (2) the various information categories ('category' illustrations); and (3) smaller icons for buttons within the website ('icon' illustrations). Whilst the review process for the 'category' and

'icon' illustrations were straightforward, the illustrations of 'people' were harder to settle on.

Although it was decided that the illustrations of 'people' would draw on the visual style of an open-access design library and the front-end design of the website¹¹⁶, there was some ambiguity around how the illustrations would depict a given setting. Stakeholders within NAT wanted these illustrations to have greater detail and show more situational context than were in initial sketches, however they were unsure as to what to request specifically. The project was further constrained by time limitations among all parties involved.

To help support decision-making, I created a series of illustration prototypes on 14 February 2019. These included a series of six digital illustrations that used the existing visual language of the website to depict various options on a three-point scale (from 'small' to 'large') in two categories: abstract or illustrative background elements (see Fig. 20-21 below).

¹¹⁶ These visual design choices had been previously discussed and decided upon between NAT and the digital agency. Open-access illustrations from the Humaaans design library (Stanley, 2021) were used for the human figures within the illustrations.

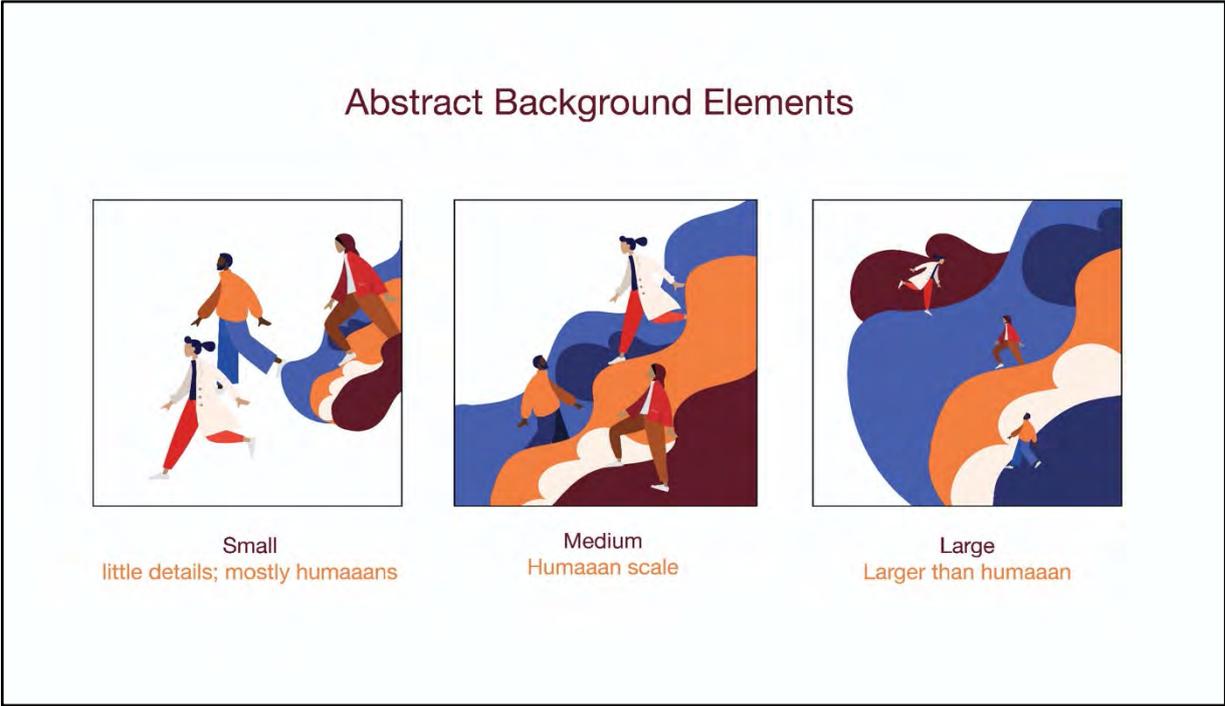


Figure 20: Illustration prototypes for 'Looped in' abstract background elements, shown on a scale from small to large. Image credit: Author.

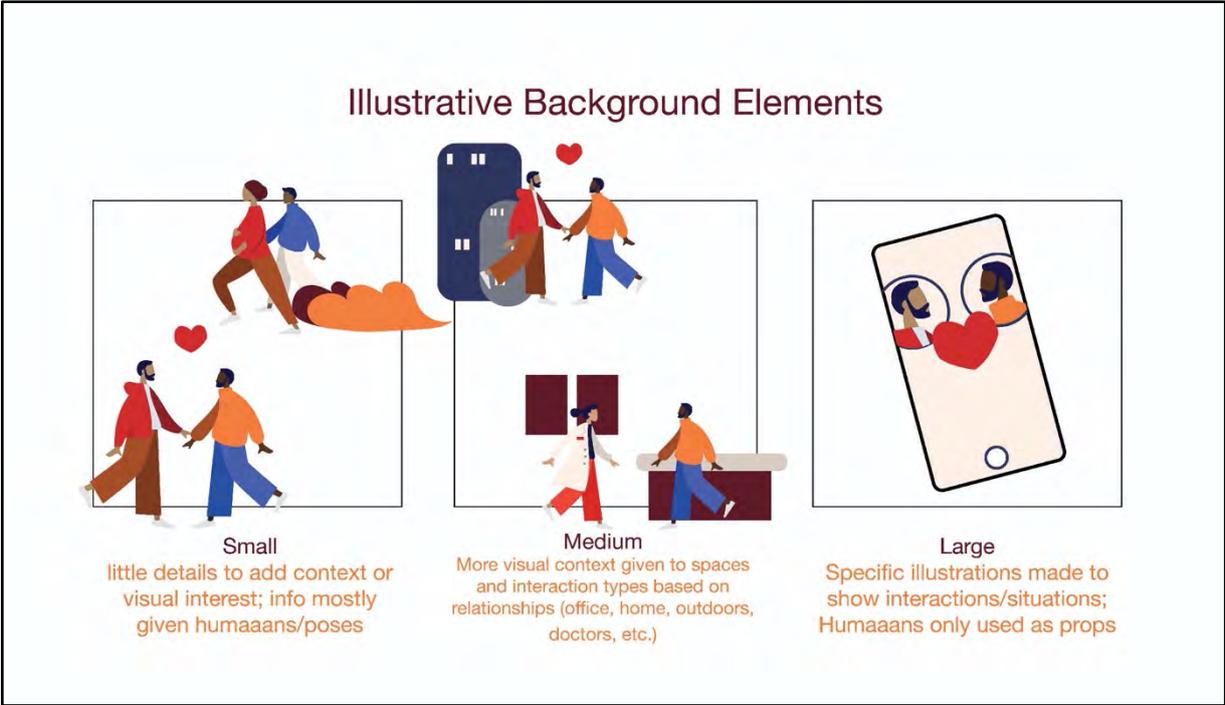


Figure 21: Illustration prototypes for 'Looped in' illustrative background elements, shown on a scale from small to large. Image credit: Author.

I used the illustrative prototypes as a tool to elicit specific design requirements for the illustrations from stakeholders within NAT. Stakeholders were able to easily and quickly identify which illustrative elements they were most interested in, unanimously deciding upon 'small' abstract elements and 'medium' illustrative elements to keep focus on the situational use of the digital tool. Internal stakeholders remarked on the utility of the tool for clarifying available options and the ease of its simple and direct format. These choices were then forwarded to the design team at the digital agency (along with the illustrative prototypes) to inform the development of the final illustrations, as seen on the 'Looped in' homepage (see Fig. 22). These illustrations were approved without further edits.

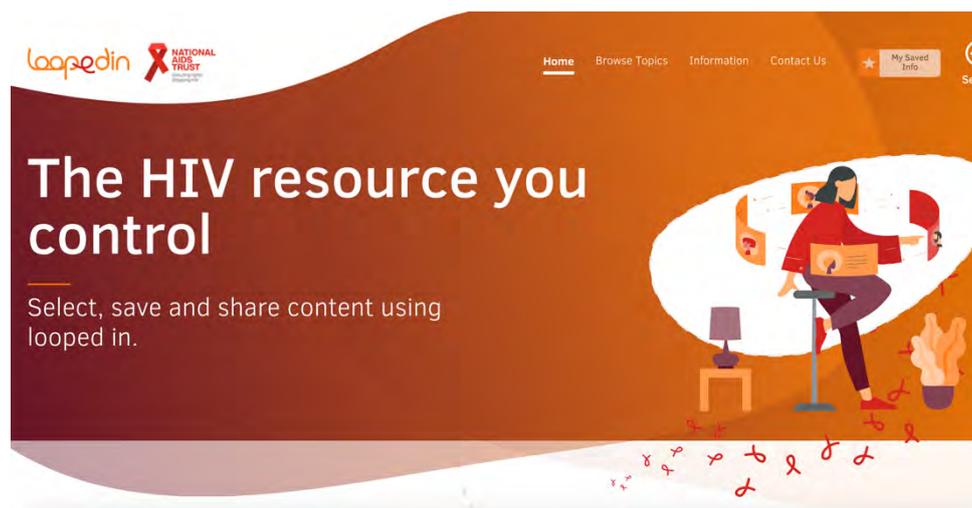


Figure 22: Homepage of the 'Looped in' website, showing one of the final illustrations of a person choosing informational content. Image source: <https://loopedin.nat.org.uk/> (Accessed 15 July 2021).

1.1.6.3 Reflections on Praxis

When considered in relation to the Design Praxis Matrix this design activity is simple, moving from Making (visualising concepts) to Defining (see Fig. 23). NAT stakeholders were able to reach a quick decision easily by comparing detailed examples along a scale, these choices then offering clear guidance for final illustrations. This

approach worked well for collaborators at both NAT and the digital agency, providing clear and defined design decisions that everyone could understand.

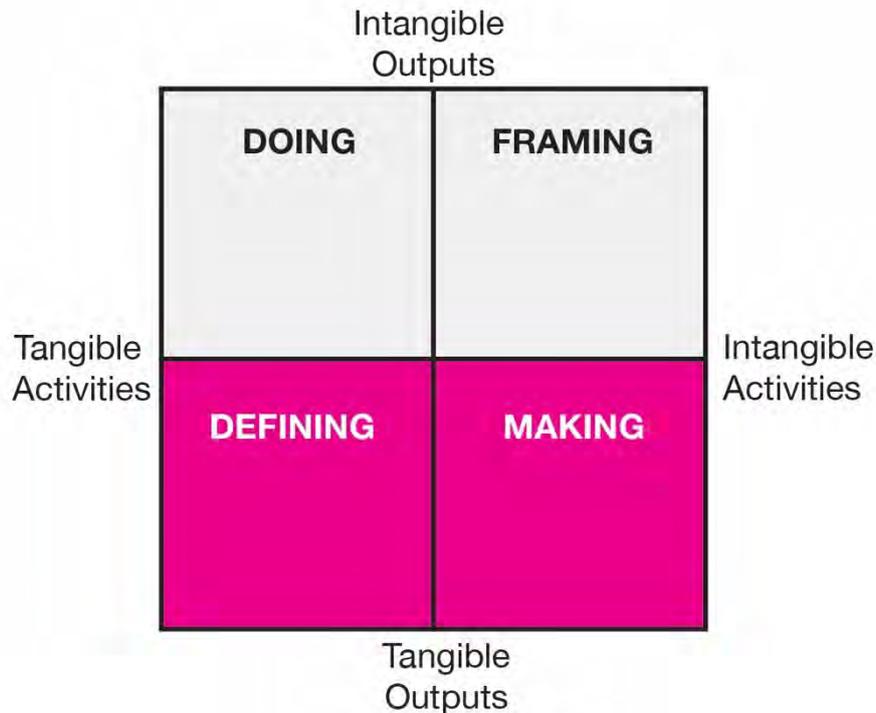


Figure 23: The illustration prototypes mapped onto the Design Praxis Matrix (in pink). Image credit: Author after (Chung, 2019).

As the project unfolded, I increasingly used sketching as a way to communicate ideas to the various collaborators. This choice was informed by the previous limitations of the internal report and success of the prototype workshop; tangible representations had continually worked better for all collaborators. Providing detailed illustration prototypes (as opposed to rough sketches) also helped better define desired visual attributes, as there was little ambiguity as to how visuals should be arranged.

Providing a scale of images supported NAT stakeholders to easily clarify what they wanted these illustrations to communicate. Whilst

the two categories (abstract and illustrative elements) are straightforward, the trio of illustrations depicts how small changes can affect the Framing of final illustrations (and thereby what they communicate). For example, depending on the size of illustrative elements, the focus of an image can be purely on people, the situation people are engaged in, or on the interaction within a situation that the user may want to use the digital tool for. These tangible prototypes provided clear examples of how visual changes could affect communication, making these intangible understandings explicit.

The visual design of the digital tool was very important for users because of how it would affect the acceptability and trust of the information shown. The visual design of illustrations within 'Looped in' was a key contextual consideration in how this tool could help support people living with HIV in complex and potentially delicate situations. The production of appropriate illustrations was therefore critically important. However, defining what these illustrations should be, given the amount of work needed to make a complete digital tool, was difficult. This process also required a design praxis that could translate contextual Framing into a Defined visual form – a translation that the internal report had limited success with previously. The illustration prototypes proved to be a successful tool for overcoming this challenge by providing a tangible representation of how visual arrangements would affect communication. Using this tool helped NAT clarify what they wanted the illustrations to communicate (and thereby look like) and provided the digital agency with clear examples of how to approach the creation of key illustrations.

This highlighted a key factor in designing digital tools for an HIV context: the defined aesthetic form of what you make matters. Using

tangible outputs (the illustration prototypes) allowed this understanding to be clarified by NAT stakeholders in a way that could provide clear design guidance for the digital agency's illustrator. This instance highlighted to me a specific area in which 'expert' design praxes may be useful within this kind of collaborative project; Making processes, or the way in which designers create forms or visualise concepts, may not always be easily accessible for HIV service providers. If those responsible for representing the abstract knowledge on a collaborative project are unable to communicate how that concept is visually applied, we have an issue, as an external design partner may be unable to access that information. The illustrator on this project needed clear guidance on what they were to create. Providing a range of visualisations to NAT helped support them to define the visual language that best communicated what they wanted to say and relay this to the illustrator.

5.4 Reflections

My internship experiences as a design practitioner working on the development of 'Looped in' at NAT has helped shape my understanding of how designers may usefully position themselves alongside HIV service providers. My work was largely translational within this project, moving between activities involving tangible and intangible aspects of digital product development in order to 'frame' and 'define' attributes as needed. This echoes the reported experiences of other communication designers working within HIV contexts, who have noted the importance and value of the *translational* abilities of 'expert' design praxis within collaborative projects (Wizinsky, 2019). The three design activities reflected upon in this chapter speak to my own developing sensibilities and learning about how to work effectively in a project team.

The three highlighted design activities illuminate the importance of using tangible outputs (or representations of designed forms) as translational tools within collaborative projects. As a design practitioner I had been guided by empathetic approaches, after Stein (3.2.1.1), in the collaborative design process when making tangible artefacts; making tangible examples of things to ensure that what I thought X should look like and what you thought X should look like were the same thing¹¹⁷. However, I had not anticipated that this approach would also be key to translating contextual understanding between professional collaborators within digital projects.

As a communication designer it has felt straightforward for me to move between the four areas of the Design Praxis Matrix in my account of this internship work – it is an ability developed through professional training and experience. Within this internship it appeared that the respective responsibilities and positioning of the collaborators guided how they applied their expertise to each other's area of the Matrix – NAT being expert in intangible outputs (or contextual knowing) and the digital agency being experts in tangible ones (or designed digital forms). I was positioned in the middle of this division with the ability and opportunity to touch upon all areas of the Design Praxis Matrix – working as translator and messenger across the (in)tangible praxis borderline. Through reflection, I understood the importance of this role when developing digital tools in an HIV context because of the importance of contextual considerations to the success of digital HIV interventions.

Making activities have been highlighted for their significance in giving aesthetic form to abstract ('non-idiomatic') knowledges and providing the means for collaborative understanding within Interaction Design

¹¹⁷ Referred to as a 'synthesising objectification' within Edith Stein's theory of empathy (E. Stein, 1989).

discourse (Bowen et al., 2016; Löwgren, 2016). Contextual understanding (or Framing), an intangible output of an intangible activity on the Design Praxis Matrix (Chung, 2019), has been repeatedly shown to be a key factor in successfully developing digital HIV interventions. However, if this understanding is most accessible via tangible outputs within a collaborative design praxis (as in my experiences within this project), *then it is crucial that Making activities are informed by appropriate contextual understanding*. This will allow the defined form (what is made) of digital projects to be informed by how it will be used in context.

However, connecting intangible contextual understanding to Making activities can be difficult in collaborative projects due to the division of responsibilities and knowledge between stakeholders. In this project, NAT was responsible for contextual knowledge about users while the digital agency largely led the Making activities. As a result, supporting the translation of contextual knowledge *through* Making activities and outputs was key to my role of supporting the development of an appropriate digital tool. Within the team, I contributed this translational link, using Making activities to translate abstract knowledge about users into tangible representations of user experiences or design requirements. By translating these insights through Making tangible things (e.g., illustration prototypes) I could create what Jonas Löwgren refers to as “responsive experimentation environments” (Löwgren, 2016, p. 30)—opportunities for users (or user representatives) to experience that representation of our understanding and provide feedback on it.

In my experience of working within this project, key activities that used tangible Making to elicit or refine contextual knowledges, such as the community review workshop and illustrative prototypes, helped address the division of (in)tangible knowledges between

stakeholders. Feedback provided by participants within the community review workshop was far more effective at translating contextual understanding than the Internal Report because it applied contextual information to a tangible output: “*this page* should not have a log-in because I have too many log-ins” rather than “there should be no log-ins because people may have a lot of log-ins”. Likewise, the illustrative prototypes provided examples as to how visual designs would affect aesthetic communication, helping NAT stakeholders to clarify how illustrations could be best made to serve contextual use concerns. Supporting the translation of abstract knowledge via tangible Making activities was unique to my role within the team, as I worked for NAT rather than the digital agency and thus could focus on how abstract knowledge (such as contextual use) translated into design requirements. From this point I could then communicate these requirements to the digital agency, conveying their feedback to NAT in turn.

This consideration highlights an area in which ‘expert’ design praxes may be meaningfully positioned to support responsible digital innovation within stigmatised health contexts. Because stigma is a subjective social belief, understanding how to design tangible artefacts and services in relation to it requires intangible knowledge of how stigma affects users. However, service providers may lack resource or design fluency to translate this abstract knowledge into a designed form; an issue raised within evaluations of Experience-Based Co-Design research in Health (Donetto et al., 2014). Conversely, expert designers removed from the context of HIV service provision, such as myself and collaborators within the digital agency, likely bring their own intangible understandings and assumptions to the table when crafting the form of digital tools and

services. As a designer positioned alongside a service provider¹¹⁸ (rather than one responsible for delivering the final digital tool) I was able to translate between these two areas of expertise using Making activities, ensuring we made something appropriate and relevant to the contextual needs of users and NAT.

Making activities help elicit and refine intangible insights in response to what is made, supporting the translation of abstract knowledge through designed form(s). This is useful for rendering abstract knowledges sense-able; NAT understanding how their intangible knowledge could be translated through designed form, and the digital agency understanding the design requirements of a digital tool within the context of HIV. In order to design effectively within the context of HIV, we need to understand how the abstract knowledges of users and service providers affect designed form. Making activities help support collaborative efforts within stigmatised health contexts by providing tangible forms of abstract knowledge in a way that is still open to definition—allowing for unconscious choices or assumptions to be rendered visible, and thereby open to conversation between collaborators.

5.5 Summary

Experiencing how a digital HIV social support tool was collaboratively developed first-hand has provided me with invaluable insight into how design praxes are used within digital developments projects. This experience informs my response to my second research question (RQ2): *How are digital tools and services designed and used within HIV social support services for women living with HIV in the UK?* Working alongside NAT in collaboration with a digital agency

¹¹⁸ Service Design scholar Laura Warwick refers to the role of the service designer within this position as a 'Critical Friend' (Warwick & Young, 2016).

highlighted the importance of collaborative and community-based design approaches within the sector, as well as the project development structure informed by the grant-based funding model for digital innovation projects. In the creation of bespoke digital interventions design expertise was contracted for a specific project, highlighting the importance of sharing intangible knowledge quickly and clearly to inform appropriate design choices.

Critical reflection on my role and contribution to key design activities within this project's development highlighted the importance of tangible Making activities when co-designing such digital tools and services. This provided insight that has enabled me to start addressing my third research question (RQ3): *What approaches can inform design praxes involving Digital Health tools and services within stigmatised health contexts?* Critical reflections on my experiences within this internship illuminated a key component of design praxis invaluable to the development of appropriate digital tools and services, given the importance of context to the success of digital HIV interventions. Through Making, 'expert' designers may support the co-creation of forms that appropriately communicate meaning by using tangible outputs to elicit intangible understanding amongst all collaborators, helping render intangible knowledge sense-able and thereby open to interpretation. This helps define final outputs and clarifies understanding between collaborators.

While this experience provided insight into the creation of a new, bespoke digital tool called 'Looped In', I now turn to report on a second empirical study that I conducted. The research described in Chapter 6 focused on a digital intervention that uses a commercially available digital tool, WhatsApp, to provide a bespoke digital support service for women living with HIV from across the UK who work as peer mentors. Through this entirely collaborative research study, I

respond to all three of my research questions, via exploration of a digital HIV intervention made *for* and *by* women living with HIV in the UK.

6 Supporting the Supporters: Digital HIV Peer Support for and by Women Living with HIV in the UK

6.1 Introduction

Digital technologies have been recommended as a way to support the provision of HIV peer support services¹¹⁹, allowing service users to select options for support that meet their needs and preferences (Positively UK, 2017). Previous work has demonstrated the need for digital HIV peer support services to adapt to individual requirements (Simoni et al., 2015; Singh et al., 2017), which may change over time and through use (Laurence et al., 2019; Senn et al., 2017).

Information Communication Technologies (ICTs) are well suited to address such requirements via customisable features. Within the HIV sector, existing, publicly available ICTs such as WhatsApp are utilised for service support provision; offering customisable features such as levels of notification for messages received. It has been suggested that such platforms could be more effective than bespoke tools (such as bespoke apps) by “integrating interventions within existing online social environments” (Warner et al., 2019, p. 1); utilising ‘ordinary’ communication channels that work to normalise communications around HIV. However, the use of such channels in community-led peer support service delivery is largely under-explored (Taggart et al., 2015).

¹¹⁹ Digital services being in addition to in-person services, not a replacement of.

The studies reported in my previous chapters focused on how digital tools have been meaningfully used within in-person peer support services for women (Chapter 3) or have been created to serve a specific purpose (Chapter 4). This chapter now looks at the experiences of women living with HIV who have utilised publicly available digital tools (such as WhatsApp) as means to facilitate a social support service: how they use a digital service that they have designed for themselves. Through this study, I was able to further address my first two research questions (RQs), how lived experience impacts the conceptualisation and use of digital technologies (RQ1) and how digital tools and services are designed and used within HIV social support services (RQ2) for women living with HIV. These insights also inspired my response to my third RQ¹²⁰, as I had the opportunity to empirically engage with a community-based and led approach to designing a Digital Health service within a stigmatised health context.

This chapter focuses on my work alongside 4MNetwork (4MNet), a peer support organisation made by and for women living with HIV in the UK. 4MNet has used digital tools, primarily WhatsApp¹²¹, as a way to support communication between geographically dispersed peer mentors (referred to as 'Mentor Mothers'), as they collectively support women living with HIV on their journeys through pregnancy and beyond. As part of my doctoral work, I collaborated on an interview study with a peer researcher working at 4MNet, exploring the experiences of 4MNet Mentor Mothers (MMs) [n=5] and project management team members (PMTs) [n=2] using 4MNet's WhatsApp group. We used Interpretive Phenomenological Analysis (IPA) (J. A.

¹²⁰ RQ3: What approaches can inform design praxes involving Digital Health tools and services within stigmatised health contexts?

¹²¹ WhatsApp is a freeware (free-to-use) digital platform (app and web) for messaging that supports text messaging, voice messages, voice and video calls, and sharing multiple file and content types using an Internet connection.

Smith et al., 2009) to analyse how WhatsApp is used by participants for 4MNet service provision, highlighting common and individual patterns of experience.

Feminist Design scholars have discussed how the realities of digital innovation may be unjustly rewritten; commentators extract knowledge from marginalised communities to talk about technology use without members' consent or acknowledgement¹²² (Costanza-Chock, 2020). In seeking to illuminate existing digital innovation by HIV social support service providers I purposefully worked alongside 4MNet representatives to highlight their knowledges rather than extract and repackage them as my own insights. 4MNetwork has led the way for others to consider how digital interventions may be meaningfully designed and used by and for women living with HIV in the UK and beyond, and it has been a privilege to be able to work with and learn from them.

This study responds to three collaboratively defined research questions (SRQ) that emerged during analysis:

(SRQ1) What does 4MNetwork use WhatsApp for?

(SRQ2) Why does WhatsApp work or not work as a platform for Mentor Mothers?

(SRQ3) How does the 4MNetwork WhatsApp group maintain the values of the 4MNet programme?

The main objectives of this study were twofold:

- (1) To gain empirical insight into what factors impact digital technology use by women living with HIV in the UK, based on their reported experiences;

¹²² Marginalised communities have been noted to have a strong information advantage with which to lead innovation activities, combining specialised knowledge with the low costs of testing within everyday life (Costanza-Chock, 2020).

(2) to provide empirical insight into how digital tools and services are (2.1) *developed* and (2.2) *used* in the field by women living with HIV.

This study has been reported on, in part, in a recent publication (Hay et al., 2020). In this chapter, I provide a comprehensive account of the work with 4MNet, reporting on the collaborative praxis involved, and all resultant insights from the IPA analysis. In doing so, I highlight the factors impacting how women living with HIV in the UK use technologies within their daily lives (RQ1); and how digital tools are created and used by women living with HIV for social support provision (RQ2).

6.1.1 Background

4MNetwork (4MNet) is a peer-led mentorship programme led by Black migrant women¹²³ for women living with HIV across the UK (4MNetwork, 2021). They train women living with HIV to become peer mentors, referred to as ‘Mentor Mothers’, providing psychosocial support for other women living with HIV experiencing pregnancy and beyond (ibid.). 4MNet began as a UK-wide initiative funded by Positively UK as part of the ‘From Pregnancy to Baby and Beyond’ project, running from 2012-2015, before being adopted by the Salamander Trust in 2016 and being resourced as a residential peer training programme. Since then, 4MNet has expanded to providing training workshops in Kenya and Uganda (called 4M+), and registered as a Community Interest Company (CIC) in 2019.

4MNet takes a holistic approach to providing peer support through the pregnancy journey, rather than having a narrow biomedical focus

¹²³ “4M is a unique peer-led programme led by Black migrant women. We train women living with HIV across the UK. as Mentor Mothers to provide psychosocial support to peers in their pregnancy journey and beyond” (4MNetwork, 2021).

¹²⁴. In taking this approach they respectfully consider the unique and intersectional needs and concerns of individual service users; Mentor Mothers (MMs) work collaboratively with their mentees to shape service delivery to their needs (4MNetwork, 2021).

In addition to providing training for peers to become MMs and provide one-on-one services, 4MNet also operates a national network connecting MMs to each other for professional support. 4MNet uses various digital platforms to support this professional training and support network, including delivering videoconferencing webinars on Zoom; regularly emailing newsletters; and operating a channel for group communication via the messaging app WhatsApp. The combination of 4MNet's holistic approach to social support and their use of existing digital technologies for service provision offers an example of how HIV social support service providers may utilise digital technologies in contextually appropriate ways for women living with HIV.

I was introduced to 4MNet through one of my doctoral supervisors, Shema Tariq, a former Chair and current member of 4MNet's Steering Group. After connecting through email, 4MNet management team members Alice Welbourn and Angelina Namiba, a 4MNet peer researcher, and I discussed how we could collaborate on research involving 4MNet's use of digital technologies for peer support delivery

¹²⁴ Through their service provision 4MNet seeks to shift the narrative within Mentor Mother peer support services from a biomedical focus (ie. 'elimination of Mother to Child Transmission') to a sexual and reproductive health and rights (4MNetwork, 2021).

6.2 Methods

6.2.1 Study Design & Ethics

This study used a CBPR approach (Coughlin et al., 2017), conducting all research activities from study design to dissemination alongside collaborators at 4MNetwork, including a peer researcher. This included several stages of iterative review and revision, detailed within the graphic below (see Fig. 24). In this chapter, I use ‘we’ rather than ‘I’ to represent the collaborative ownership of research activities as appropriate (3.2.2).

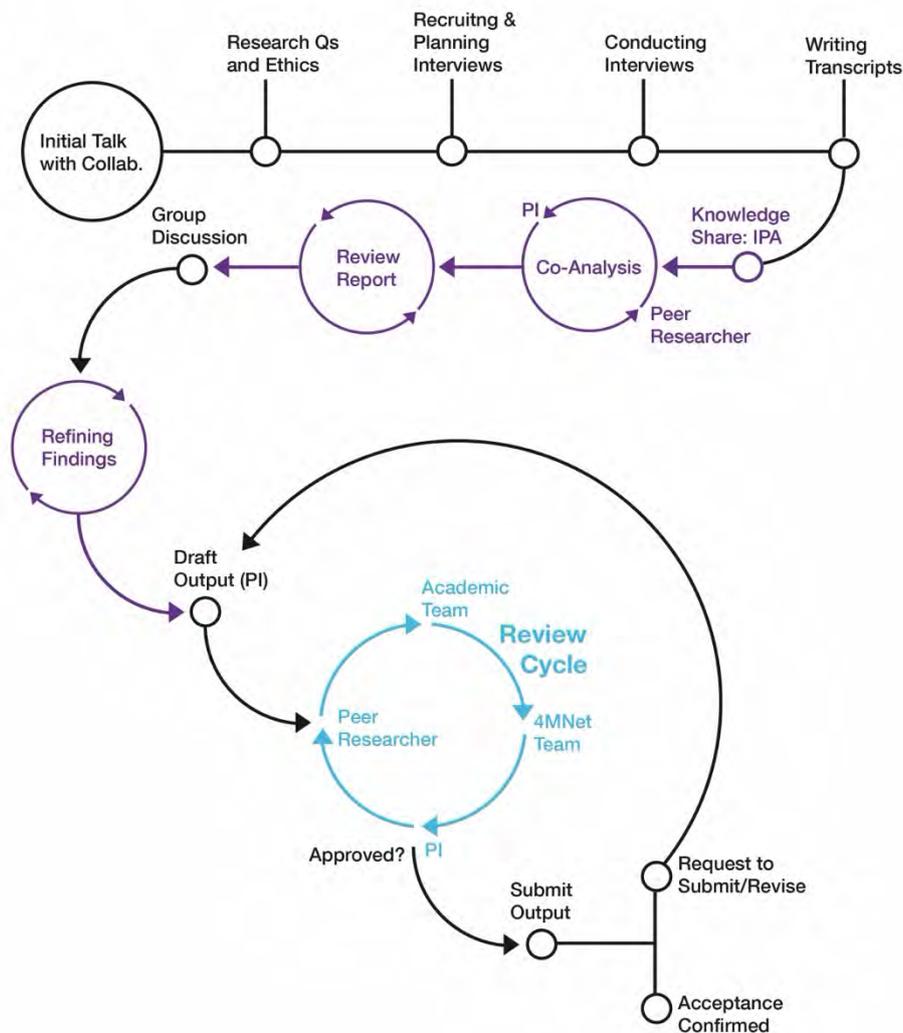


Figure 24: Graph mapping the unfolding and iterative research process of the 4MNet Study, highlighting key moments of review and revision. The Author is represented as ‘PI’ within this graph. Image by Author.

We chose to conduct telephone interviews with several MMs and project management team members (PMTs) to explore individual experiences of using the 4MNet WhatsApp group. We decided that the 4MNet stakeholders involved in the initial study planning would also be participants within the study as PMTs, to support the inclusion of participants within analysis without placing undue burden on them. This was in line with the 2017 consolidated guidelines on sexual and reproductive health and rights of women living with HIV (WHO, 2017) and best practices within the HIV sector (Kumar et al., 2015; Namiba et al., 2016).

We also decided to analyse interview transcripts using IPA, because of its phenomenological focus on individual lived experiences and meaning-making (Lyons & Coyle, 2007), allowing for both individual and pluralist insight to be illuminated (J. A. Smith et al., 2009). IPA's idiographic approach to inquiry was well suited to our study aims and objectives, as we were investigating experience within a specific context with limited membership and access (ibid.). We used purposive sampling to capture specific, situated experiences of members of 4MNet, hoping to use insights from this study to inform future research, policies, and service design within the HIV field (Brocki & Wearden, 2006).

The peer researcher and I then drafted the semi-structured interview questions (see Appendix E.2.3). Once completed, I prepared and submitted an amendment to my initial Ethics application to Northumbria University, which was approved on 10 January 2019 (see Appendix E.1). The peer researcher then recruited participants internally from within 4MNet's WhatsApp group, using convenience sampling to ensure group and individual privacy.

I conducted interviews independently by telephone or via Skype, depending on participant preference. Calls were recorded with a call recorder app for Skype and/or a telephone audio recorder, with informed consent. Participants were remunerated with a £10 shopping voucher for their time. The peer researcher and I transcribed and anonymised audio recordings immediately following the interviews, deleting the original audio recordings once completed.

6.2.2 Participants

We recruited seven participants for the study, including five MMs and two PMTs. The mean age of participants was 49.7 years, with 80% of participants reporting their ethnicity as Black African (Hay et al., 2020) ¹²⁵. Other characteristics are detailed in the Table 4 below.

Table 4: Participant demographic information from the 4MNet interview study.

Participant [P#]	Age	Location within UK	PMT or MM
P1	44	London	MM
P2	52	South of England	MM
P3	44	London	MM
P4	57	London	MM
P5	40	Scotland	MM
P6	60	South of England	PMT
P7	51	London	PMT

¹²⁵ Participant demographic information within Table 4 has been purposefully limited to respect the privacy of participants.

6.3 Analysis

The peer researcher and I collaboratively analysed the transcripts using IPA, coding the transcripts individually before gathering our codes together for collective analysis. Codes were manually coded through a two-step (“double-hermeneutic”) process: first coding how participants made sense of the interview, reflecting their actual words when possible, and secondly coding how we as researchers interpreted participants’ sense making to address our study’s research questions (J. A. Smith et al., 2009). Our individual codes were then collated and grouped into initial themes through discussions between the peer researcher and myself (see Fig. 25 below; also Appendix E.3).

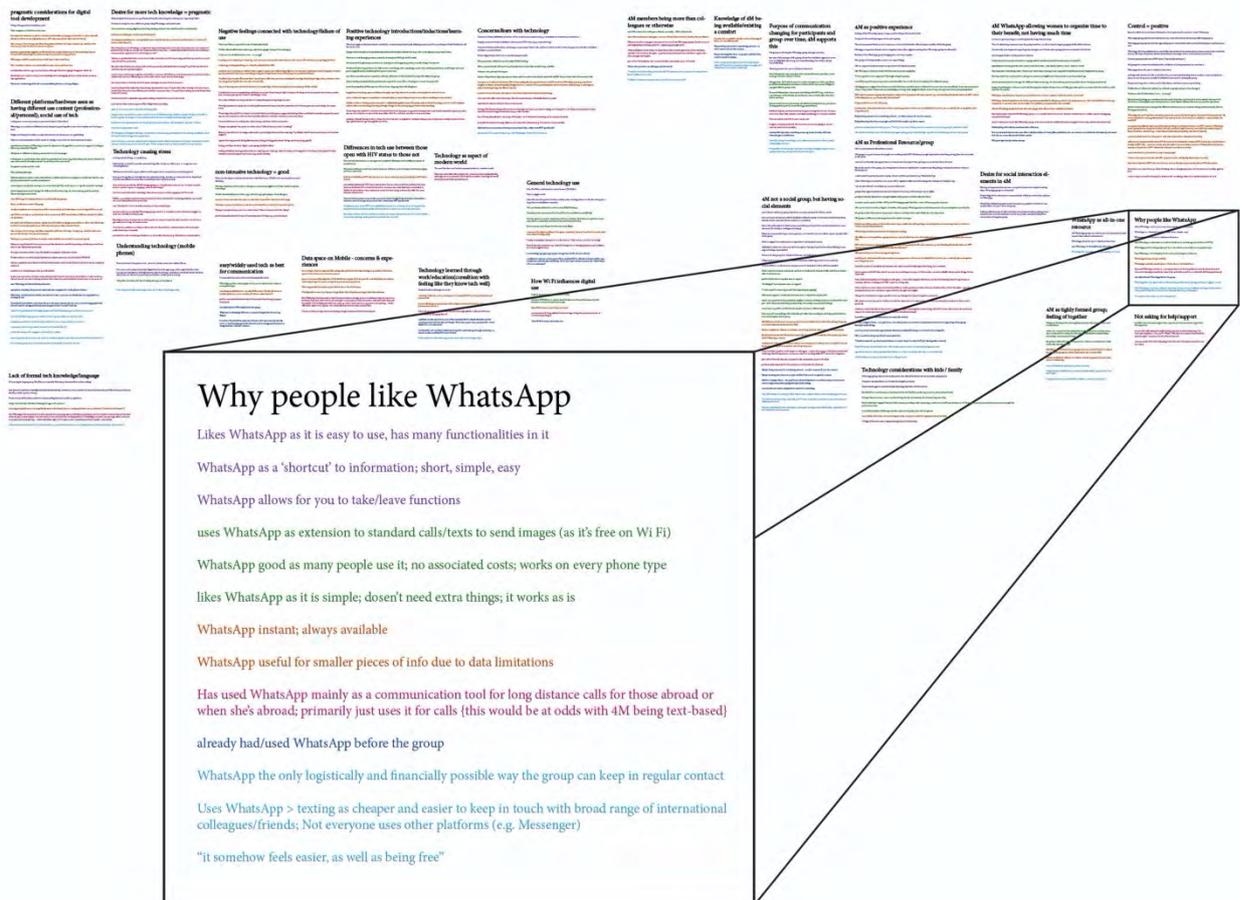


Figure 25: Codes sorted into initial themes from the 4MNet Interview Study (see Appendix E.3 for further details); codes involving why some participants enjoyed using WhatsApp highlighted. A unique colour was used for each participant. Image by Author.

These initial themes were then analysed using abstraction to form three super-ordinate thematic categories, framed in response three study research questions (SRQ1-3) co-produced between us. I drafted a study report to summarise and present the themes in relation to key participant quotes and the initial themes; the peer researcher reviewed this initial report and agreed with the representation of themes (Appendix E.3). We presented the themes and report to collaborative stakeholders at 4MNet and my supervisory team members to further refine and consolidate the super-ordinate themes. This multi-stage process supported reflexive engagement with the codes both individually and collaboratively, allowing for discrepancies to be addressed, discussed, and resolved.

IPA is concerned with how the experiences of researchers impact data interpretation. I will therefore provide some detail about who was involved in the analytic process. Collaborators included myself and the peer researcher; two 4MNet stakeholders, who were also participants within the study as PMTs; and three members of my doctoral supervisory team, which comprised two academics with expertise in HIV and technology design, and an HIV physician and medical anthropologist specialising in women's health. The interdisciplinary experience represented within this collaboration allowed for rich and multifaceted discussion. Furthermore, the inclusion of 4MNet members and study participants within these stages supported (1) the goal of IPA for individual experience to be represented through the analytic process; and (2) methodological alignment with guidance on the meaningful engagement of women living with HIV within research (Hay et al., 2020; WHO, 2017).

6.4 Key Findings

I now describe the resultant themes from this study. Participants' contributions have been anonymised, their names represented by [P#]. For this account, there are three super-ordinate themes, framed in response to three study research questions (SRQs) developed collaboratively with the peer researcher from 4MNet (see Fig. 26 below). The first three Key Findings subsections (6.4.1-6.4.3) will describe the identified themes in response to this framing. The fourth subsection (6.4.4) will then briefly illustrate and describe the interconnections between these thematic categories as they relate to the main research questions (RQs) of my PhD project, providing further insight from this collaborative study.

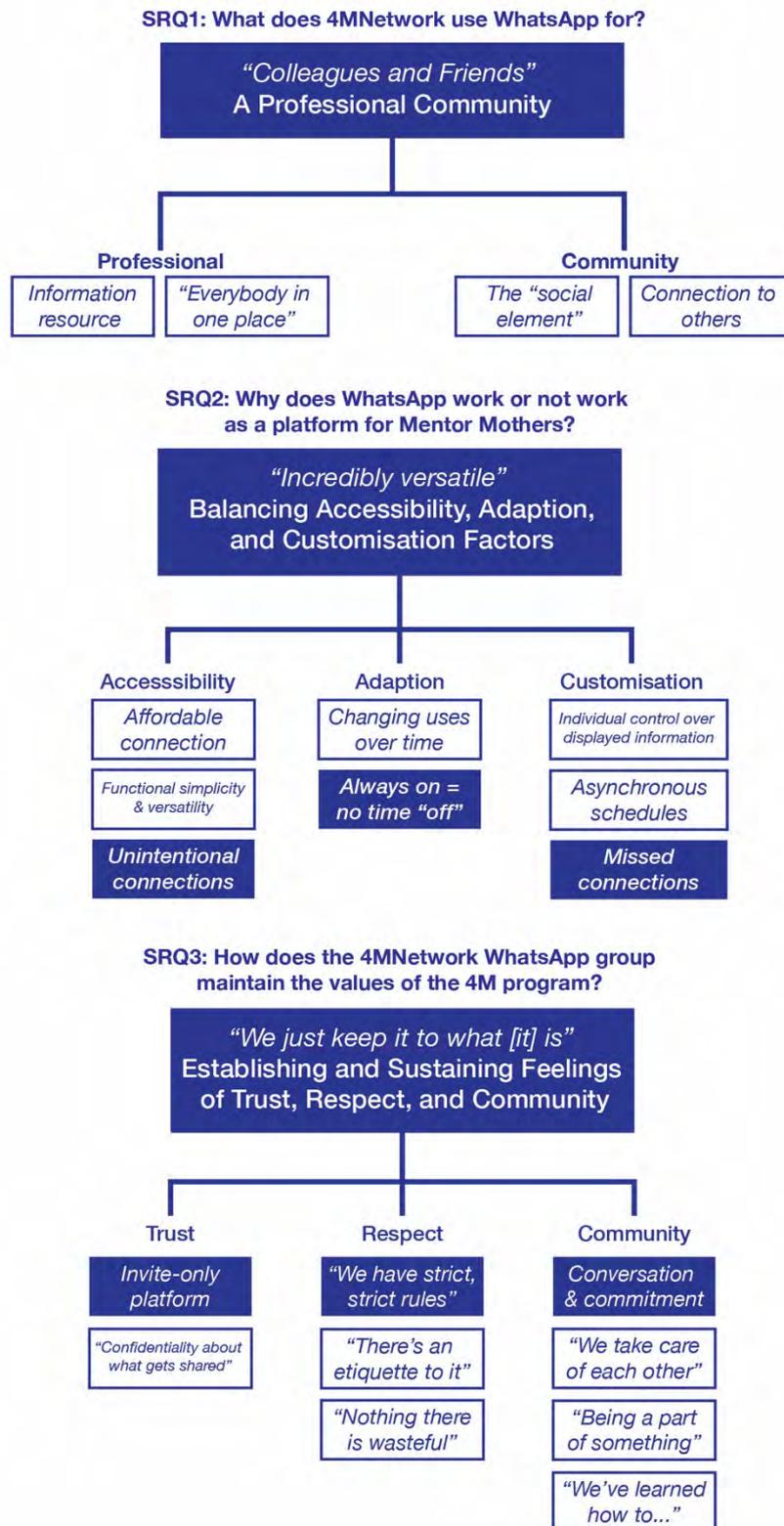


Figure 26: Thematic mapping of the three ‘super-ordinate’ categories in response to the emergent study research questions (SRQ1-3) of the 4MNet interview study.

In order to reflect the plurality of voices within this study some themes include excerpts that illustrate the contradicting opinions of some participants, highlighting the complexity of service provision within this space. This has been noted where applicable.

6.4.1 **“Colleagues and Friends”**: 4MNetwork WhatsApp Group as a Professional Community (SRQ1)

The participants’ voiced experiences of using WhatsApp for 4MNetwork activities illustrated how the group was viewed as a professional community, a network valued for its professional and community elements (see Fig. 27). The 4MNet WhatsApp group was established as a means for MMs and members of the PMT to stay in contact.

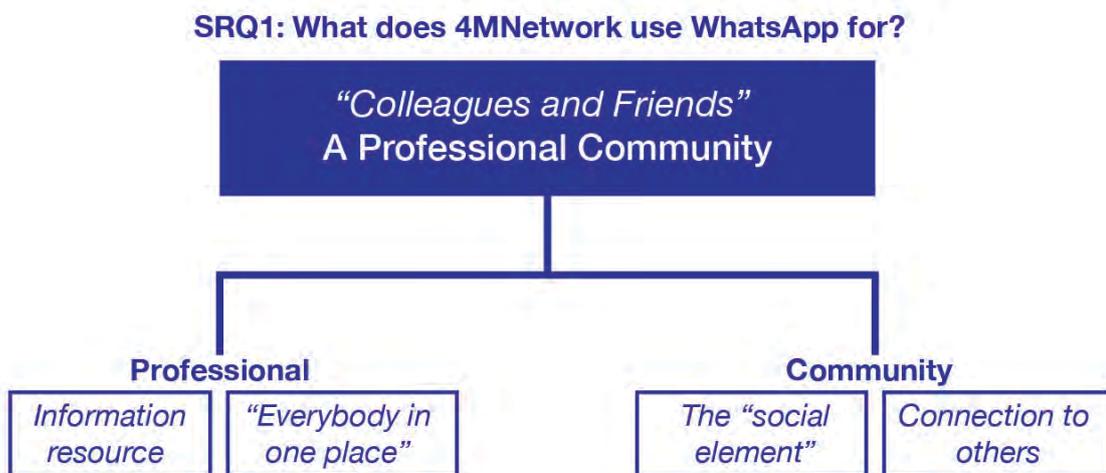


Figure 27: 4MNet interview study super-ordinate theme and subthemes mapped in response to SRQ1.

P1 described how she viewed the balance between these two aspects of the group’s relationship:

“I think it’s... colleagues and friends. It’s colleagues because we don’t see each other much and of course within the group there is um a lot of boundaries... we are friends, but it’s more... professional minded kind of (pause) group. I think,

well that's when we're in that network; in that WhatsApp group it's strictly work-related, so it's more a colleague mindset.” [P1]

As a MM within 4MNet, P1 viewed relationships as friendly but professionally focused within the WhatsApp group. The content shared within the group was strictly work-related, setting boundaries between social and professional conversations. This made P1 feel that the tone within the WhatsApp group invited “a colleague mindset”, as the group didn’t often see each other in-person and therefore used WhatsApp as their main point of mediated contact.

P7, a member of the PMT, also highlighted how peers within the group were viewed as colleagues, while expanding on the underlying community aspects of the group:

“[the relationship on WhatsApp is] more as colleagues, it's a good relationship and more as colleagues. There's a few of [the group members] who I have known over the years who I can also term as friends... but also, you know what actually? I also see them as a family because in a way we share a lot of things that are intimate sometimes, both for support but also for information. I just think the bond is closer than the everyday There is a lot more connection than just colleagues.” [P7]

She described how some interpersonal relationships within the group were enriched by the informational and emotional support provided, creating a deeper relationship between members than a working one, despite the focus of the group on professional activities. This entwinement echoes the dual social and professional elements of peer support more generally, with the WhatsApp group similarly blurring the lines between the two, rather than operating purely as a professional resource.

Most of the participants raised that professional and personal relationships were blended together in the group [P1, P2, P7] or identified members as either colleagues or friends [P3, P4, P6]; P5 was the only participant who identified with others in the WhatsApp

group as ‘colleagues’ alone. While ‘professional’ and ‘community’ elements of the group were entwined throughout the experiences of the participants, key aspects of each were evident in the analysis.

One participant, P4, had chosen not to use the WhatsApp group, instead being updated by text messages, phone calls, or emails from PMTs. She noted that being involved in the 4MNet WhatsApp group might affect how she viewed relationships within the group at large:

“If I was involved in the WhatsApp group, I’m sure it would actually seem like... maybe... a more strengthened connection [with others in 4MNet]? Because it would be formed by other... mentors or mentees... mentors? Mentors, yes (laughs). You know, maybe more of a friendship kind of thing would be... uhm, happening through that... It’s good that you’ve raised it because maybe I could do that?” [P4]

Whilst P4 was not actively involved with the WhatsApp group at the time, she was aware that there was an appealing social aspect of the WhatsApp group beyond its use as a professional resource. She didn’t want to “[make] another commitment to another aspect of engaging, around work things,” however she appeared regretful about missing out on the added social value of being in the group.

6.4.1.1 Professional

All participants who used the WhatsApp group [P1, P2, P3, P5, P6, P7] valued the 4MNet WhatsApp group as a multifunctional professional resource, offering informational support and an easy connection to the entire group. PMT participants [P6, P7] also commented on the value of WhatsApp as a professional resource for team management, allowing for team communication and planning to exist parallel to the main group. As voiced by P7: “*Within the staff team we use WhatsApp to manage the project and communicate about stuff, do our work plans, meetings basically... We use it as a team tool.*” In this way WhatsApp served as a professional resource for both 4MNet MMs and PMTs.

6.4.1.1.1 Information resource

As an information resource the 4MNet WhatsApp group mediated general group-related news and events, as well as updates on the group and group members' activities. As described by P3:

"It's different [from other WhatsApp groups], because with the 4M WhatsApp group it's, mainly to do with issues you know that concerns 4M; it's to do with anything that, you know could help or that we need to know concerning 4M. We could also have outside information, as long as it, it's to benefit others in the group. And, you know, the 4M project as a whole." [P3]

She went on to comment that the WhatsApp group served as a professional informational support resource on a broad range of topics, curated to the needs and interests of the group. This included information on events or referrals that might be applicable to group members. As described by P1: *"It's a lot of... informative kind of information... like this is what's on, this is what's happening, this is what's going on, this is what you missed."* The network within 4MNet's WhatsApp group and curated informational support in line with the group's professional goals, established the group as a useful informational resource.

6.4.1.1.2 "Everybody in one place"

The 4MNetwork is comprised of individuals from across the UK, making the WhatsApp group a valuable tool for communicating with multiple members in one place. This single point of contact was a key feature valued by PMTs in using WhatsApp as a professional tool:

"My favourite part [of the WhatsApp group]... I think just the fact that I can reach all the Mentor Mothers at the same time; the immediacy, the convenience." [P7]

Being able to reach all MMs instantly made the WhatsApp platform a convenient professional tool for P7 as a PMT. This instant group communication was also valued by MMs, as an easy way to keep connected and up-to-date with other members:

“Knowing that I can reach everybody in one place and keeping updated with everybody and what's going on without really having to dig for it. Sometimes I'm not aware about [what everyone's doing], but then you see someone gave a talk here or someone doing is doing that or they've achieved that.” [P1]

P1 valued the way that the WhatsApp group collected both communication and updates together in the same place, meaning she could avoid “*really having to dig*” for information across multiple platforms or channels; this ease of use made it simpler for her to keep up to date. This was important to P1, as she described that she had limited time to engage with similar resources: “*I don't get time to go to support groups... I don't read blogs or emails much, so at least this [group] is keeping me in the loop some.*” By having everything in one place the WhatsApp group operated as a ‘one stop shop’ for P1, supporting her in keeping connected to the group and up-to-date whilst working within her available time.

6.4.1.2 Community

Several of the participants who used the WhatsApp group also valued how the platform supported the group as a community of peers [P1, P2, P3, P6, P7], adding a social element to professional communications, facilitating a supportive environment, and creating a sense of connection to others despite geographic distance.

6.4.1.2.1 The “social element”

Both MM and PMT members of 4MNet highlighted how the WhatsApp group provided a social element to professionally focused communications between members. P2 said:

“There is a nice social element in that when we do work [and talk about it within the group], we all sort of celebrate each other and say “oh well done!” or share photographs and do things like that...I like that part of it.” [P2]

This sheds light how the social aspects of the group were entwined with professional activities, aligning personal updates to the group's

professional focus. This added a positive 'social element' to individual updates shared within the group for P2, which she enjoyed.

The familiar relationships fostered by this social element within professional communications was also enjoyed by PMT members, such as P6:

"I think... I really love the [pause] the friendship circle side of it... It just seems like a real sort of sense of sisterhood. [If] somebody has done something they say, 'I've done this' and everyone says, 'Oh, that's great, well done you'; there's a real sort of sense of sisterhood there which I think is a real solidarity, which is great. It's lovely." [P6]

The underlying community operating within the 4MNet WhatsApp group imbued the supportive interactions between group members with a sense of solidarity for P6, and created a valued sense of togetherness. The 'social element' within group communications layered professional updates with a sense of connection that reflected the sense of community ("sisterhood") behind the messages; this created a supportive environment for group members.

6.4.1.2.2 Connection to others

Being part of the 4MNetwork WhatsApp group also helped foster a sense of community by bringing members together in one place, despite the geographical distance between members. This was especially valued by P5, the only participant located in Scotland:

"[My favourite aspect of the 4M Network WhatsApp group is] being connected to other women, from all over the country... it just helps me to know that there are other people that I can speak to, if I need to. Just knowing that there's that support network." [P5]

For P5, being a part of the 4MNet WhatsApp group provided a connection to a community of peers despite their living in a different part of the country. Whilst P5 also described using in-person

organisations within her local community to support her work as a MM, she said she enjoyed using the WhatsApp group because it was “easy to access”. Through WhatsApp, P5 could establish a connection to a national network of women, providing the comfort of knowing that she had easy access to a supportive community whenever needed.

The connection to peers and sense of community it created was raised as a valuable aspect of being involved with 4MNetwork for many participants. Maintaining this connection was given by P2 as the major reason she chose to join the WhatsApp group: “[I joined] to keep a connection with the 4M mothers that I met in person... it really grew out of that”. Sustaining connections to others within the community was voiced as being an important component of using the WhatsApp group.

6.4.2 “Incredibly versatile”: Balancing Accessibility, Adaptation, and Customisation Factors (SRQ2)

Analysis of how the participants described their individual experiences using WhatsApp for 4MNetwork activities showed how members balanced the benefits and concerns of three key platform attributes: its afforded Accessibility, Adaptation, and Customisation factors (see Fig. 28).

SRQ2: Why does WhatsApp work or not work as a platform for Mentor Mothers?

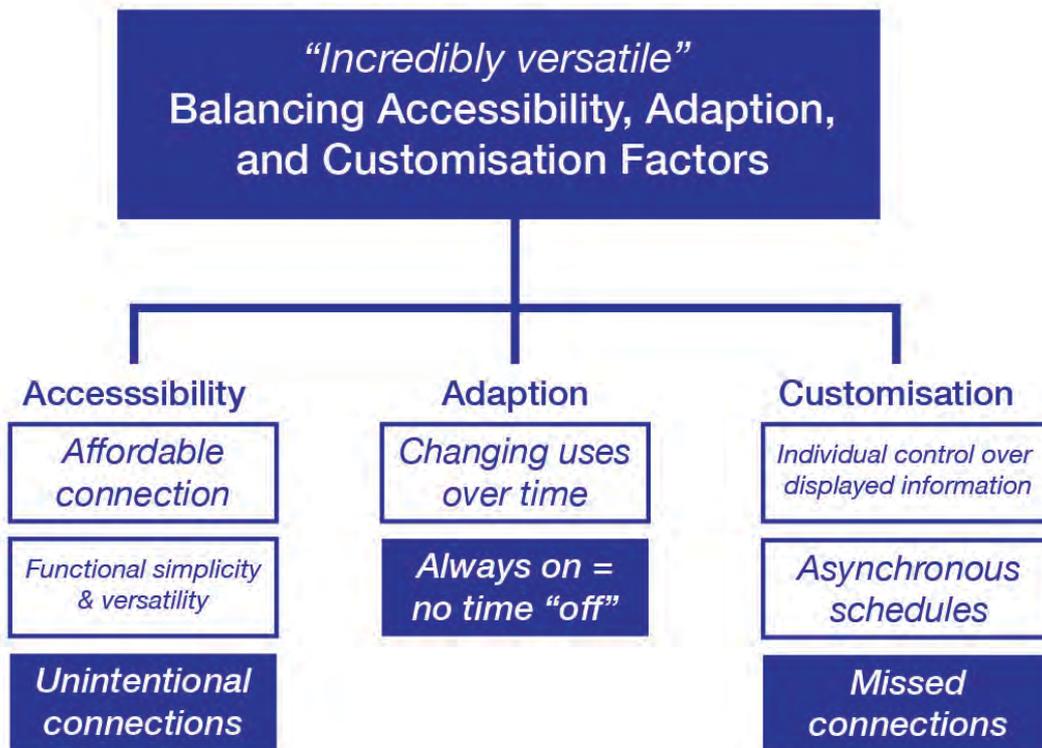


Figure 28: 4MNet interview study super-ordinate theme and subthemes mapped in response to SRQ2.

6.4.2.1 Accessibility

WhatsApp was described as being an accessible digital platform for the group because it cost nothing¹²⁶, operated across devices, and was easy to use. However, cost (of digital devices and ongoing access), familiarity, and ease of use were also concerns for some participants.

6.4.2.1.1 Affordable connection

The most immediate benefit of using WhatsApp as a communication platform for the nationally dispersed group was its low financial cost,

¹²⁶ As a freeware platform (free to download and use as a service).

as WhatsApp is free to download and use as a service. P2 explained:

“It's free and accessible... For friends who don't have iPhones, they can't send iMessages... If they've got Android... so it's possible to send them a WhatsApp [instead]”. [P2]

P2 valued WhatsApp as a free digital platform that was accessible on a variety of phone models and platforms, making it easy to connect with others regardless of what kind of phone they used. This should also be considered in light of P1's description of her family's acquisition of mobile phones:

“That's why [everyone in my family] all have iPhones. (laughs) Of course when we have one, we have one that works... When someone, um, gets the old one, we just buy the second hand one.” [P1]

P1's statement sheds light on how WhatsApp's accessibility on a range of phone models may be valued both for different phone platforms (e.g. Android or Apple) and different versions of the same model. App support for mobile phone models is generally phased out as supporting legacy versions become unprofitable to support. As a global digital platform, WhatsApp is likely to be able to support a greater range of phone models than bespoke apps, making it an accessible choice for those using an older phone model, such as P1.

P6 also discussed the importance of affordability for 4MNet as a PMT, in addition to its logistic benefits:

“Because we're spread across the country... [WhatsApp is] just a brilliant way of just keeping in touch on a much more regular basis, because we just wouldn't be able to afford the cost of... bringing people together, bringing women together, you know with that frequency. But also, logistically, I just think it would just be impossible... So, you know, the immediacy of everyone just being at the end of, you know, a text... it's much more immediate.” [P6]

P6 shared that regular in-person meetings would be both financially and logistically impossible for 4MNet, making WhatsApp an ideal alternative for maintaining regular contact due to its low cost and

immediacy. The challenge of managing group logistics was also touched on by P1, a 4MNet MM:

“I suppose that some people are not in London. It would be difficult for me personally, I work five days a week now. So even if we had a meetup group it would be difficult. Um, knowing other people outside of London as well, it’s difficult for them [to attend in-person meetings]... Because it’s not limited to people who are just in London, so it’s bringing everybody with the experience regardless of where you are so it’s really good. Because I think it allows for more experience and more opinion and more... things? Yeah, your location should not dictate what you know and what you contribute.” [P1]

This excerpt highlights the added value of using WhatsApp for P1, to address the logistic limitations of in-person meetings for the group—supporting all members to contribute to the group regardless of schedule or location.

Whilst all participants owned a mobile phone and/or computer, some noted the financial burden of continual WhatsApp usage. When considering her financial stability over the years, P2 ruminated on how her past financial experiences may be the present reality for other women living with HIV: *“Fortunately, at the moment, [I’m] in the position where I can pay for my contract... but, like, five years ago that would have been a real issue”*. Another issue regarding the cost of accessing WhatsApp was raised by P3, who noted how using WhatsApp for 4MNet activities affected her personal digital storage availability:

“With the limitations of data and things like that on the phone, you can’t have really much, you know... messages, on your phone, taking up all your space, you know, because we use our personal phones - 4M is not providing us to - to put all this extra information... I think WhatsApp is more convenient for, you know, smaller kind of pieces of information, you know, and rather than, you know, large information that would take... all your phone storage {laughs} and then you cannot take your pictures, (laughs) because you’ve got all this 4M information in your phone.” [P3]

The issue with digital storage had also informed P4's choice to remove WhatsApp from her phone in the past, referencing that she "ran out of space" for it. In response to this concern, P3 described how the group navigated this, limiting what kind of content was shared within the app to reduce its impact on individual data storage. These instances show how divisions could be created with regard to who can afford access and sustained use of a "free" digital service, and how 4MNet members tried to address these concerns.

6.4.2.1.2 Functional simplicity and versatility

Familiarity with the functionality of WhatsApp as a digital tool was valued by some participants who praised its functional simplicity, ease of use [P1, P2, P3, P7] and versatility [P5, P6]. As described by P2:

"I think the reason why it [WhatsApp] does work for me it that, it's simple. You know, it is what it is, I don't think it needs to, be more complicated than it is." [P2]

For P6, this simplicity of function meant she also used WhatsApp for different professional and personal relationships:

"I use WhatsApp for different work groups [and]... family and friend groups... I just find WhatsApp incredibly... versatile and helpful. For texting. And for work. And for friends and family." [P6]

P2 and P6 had both previously used WhatsApp for personal or professional communications, making it a familiar tool for easily connecting with the 4MNet group.

WhatsApp had been used by all participants in some capacity and was thus familiar. Potential concerns about digital confidence were raised however; Participant 4 [P4], the only participant who did not use WhatsApp at the time, spoke of lack of self-confidence when using digital tools more generally:

"I definitely feel like if I had more confidence around certain applications, it would help me a lot (laughs)... If you don't

have much confidence around something, it's hard to... make the most of it, basically.” [P4]

Although P4 had chosen not to join the 4MNet WhatsApp group because of her work responsibilities and concerns about digital storage, her statement raised how digital confidence could present barriers to access for some users upon reflection in our analysis. Some participants touched upon this issue when describing their ease in using WhatsApp. P1 voiced: *“We just learned how to use one [digital platform] and stuck with that... So we don't have to learn anything new (laughs)”*. P1 sheds light on how limiting the digital platforms used by 4MNet has supported her ease of use by minimising the amount she has to learn.

6.4.2.1.3 Unintentional connections

P3 raised concerns that the relative ease of using WhatsApp meant it was used for many group discussions, not exclusively for 4MNet activities. This non-exclusive use could lead to unintentional information sharing to other groups. P3 shared an example of how she had accidentally sent an HIV-related message to another group in WhatsApp:

“My worry is, you know sometimes, in WhatsApp, you end up sending messages... by mistake to a person that it was not intended for? That's my biggest worry. Only yesterday, it wasn't to do with 4M, it was to do with an event that I was attending [that] was HIV related... I mistakenly posted it on the group for the year one mums in my daughter's class.” [P3]

This experience had raised concerns for her around how information could be accidentally shared easily across different groups within WhatsApp, presenting a cost rather than benefit of WhatsApp's ease of use.

6.4.2.2 Adaptation

Another key factor in the effectiveness of WhatsApp, as described by the participants, was how it afforded changes in platform use over

time. They spoke of having different uses for the app over different periods of their lives, as well as using the platform differently in different contexts. The app supported participants in adjusting their individual use of the platform without needing to disengage from the group in the long term. However, this could also precipitate feeling anxious about information overload or stress. I expand upon these elements further in the following subsections.

6.4.2.2.1 Changing use over time

Some participants noted how they had adapted their service use or engagement with the WhatsApp group at various points. These adaptations were made at both an individual and group levels, based on changes in individual circumstance or group activities respectively.

On a personal level, P1 shared that she had previously adapted her use of the platform while dealing with some personal issues:

“There was a time that I that I just muted it for a while because I had a lot of... personal things happening... I was suffering from, like depression? So I was not very... busy, engaging, and also a bit withdrawn. So [a group member] would text me and say, ‘Okay, we’re doing supervision’ this or, you know, ‘when you have time, would you check in the group?’ She [would] give me slight reminders... things got better... so I’m back in the group.” [P1]

In sharing her experience, P1 described how her involvement within the 4MNet group changed in response to her personal circumstance. This was achieved through (1) her muting¹²⁷ the group chat, and (2) another member connecting with her individually when engagement with the group became difficult. 4MNet’s individualised approach to peer support allowed P1’s involvement to be configured in response to her circumstances, rather than exclude her from the group entirely.

¹²⁷ An individual user is able to ‘mute’ a group conversation on WhatsApp, turning off displayed notifications when another person interacts with the group and thereby ‘muting’ the group on their personal device without disrupting the group.

P2 also described how her involvement within the WhatsApp had changed over time in response to her career progression:

“When we first started... I did post a lot more, used it to share images. I did use it a lot then. But then I guess my work changed and the stuff that I was doing... um, has changed. Career-wise. So...I, I guess I haven't needed... [the group's] input and their information and their support so much, because I haven't been working so much in that [HIV] field as I was before. It was really useful, then.” [P2]

She voiced how her needs from the group had changed in relation to her move outside of the HIV sector professionally, now interacting with the group less. Her interactions within the group had changed over time, yet P2 reflected on the value of the group professionally to her at the time. Although her career progression had changed her interactions within the group, it had not affected her use of the group itself; her use adapting in response to her new interests and needs.

Changes to group interactions were also noted in relation to how group activities changed throughout the year. P7 reflected on her engagement with the group, noting that her use “*depends on what we are doing... [sometimes] it can be once a week, once a month... it changes*”. P2 expanded on this, reflecting on how group engagement with the group had recently changed in response to a webinar:

“When something's happening, we've got bits to say to each other. Or like, just now... we did the webinar... so there were discussions about that, and discussions before and after... but now there's been nothing... They'll be something and that will create a sort of flurry and then there will be nothing again.” [P2]

Lulls in service activities were reported to affect the use of the 4MNet WhatsApp group by some participants [P1, P2, P5, P7], as it mainly operates as a channel for group training and support. P2's statement illustrates this as a reality rather than a negative aspect of the platform, group interactions only being active when needed. Upon

reflection, this reality adds value to WhatsApp in comparison to other forms of digital communication, such as an email newsletter, for which infrequency might be a negative factor. As a messaging app, 4MNet members can adapt their use of the WhatsApp group in response to the frequency of messages without it becoming lost among other conversations.

6.4.2.2.2 Always on = no time “off”

While most of the participants voiced the adaptability of WhatsApp as a being an asset, the constant presence of the platform raised concerns for some. P3 explained:

“4M is pretty much on a voluntary basis and everything... So sometimes it's like, (sighs) oh, you just feel like it's too much work and... [you're] not getting paid for it... I enjoy using [WhatsApp], but like I said, it's instant, It's accessible anytime... It's accessible all the time. So, you have no time off and you don't want to be looking [at] work-related stuff when you're having your off time. So that's the only, you know, downside of it”. [P3]

As WhatsApp was located on P3's personal mobile phone, it was always available to her, leading her to feel that she never truly had time off from her professional responsibilities. The potential for being overwhelmed by work was voiced as the primary issue that P4 had chosen not to engage with the WhatsApp group:

“The only thing is I'm also quite overloaded with stuff {laughs} that I'm already doing, so... you know, making another commitment to another aspect of engaging, around work things; I'm not sure I should be taking on... more than I have to {laughs} have to be. Like, I still like the balance of what I do with 4M, at the moment; It's... It's enough.” [P4]

Engaging with the WhatsApp group represented another professional commitment to take on for P4, which she felt was too much in addition to her other responsibilities. The constant presence of the WhatsApp group led to stressful experiences for both P3 and P4; and this informed P4's choice not to engage with the group on WhatsApp.

6.4.2.3 Customisation

The final key aspect to 4M Network's use of WhatsApp is how the platform was found to empower the individual user to make changes to the tool and its contents, and to configure its functional features without disrupting the use of the tool for other group members.

6.4.2.3.1 Individual control over displayed information

P1 spoke about customising what information WhatsApp could display on her phone using customisable options within the app. This included 'muting' group chat notifications:

"We also have a choice; Like you can mute, you can mute it if you find [you have] too many messages are coming in, or if you're too busy or whatever, we have a mute option as well. I think that's an advantage of that." [P1]

The option to mute incoming messages on WhatsApp was viewed as an advantage to the platform for this participant, who saw the function as a choice, or a way for her to customise the app to her preference when things got busy.

P1 also raised the benefits of being able to delete messages within the group chat within her phone, without it disrupting what was being shown on other member's phones:

"The good thing with WhatsApp is that if you delete [anything] you just delete [it] for yourself. So, if I haven't posted [something] I can't delete it for everybody, but I have that choice to delete it for myself." [P1]

WhatsApp users are able to delete messages they have received on their phone alone because of its distributed messaging system; a message will only be deleted for everyone if it is deleted by the person who sent it. P1 also noted the potential to delete entire messages within WhatsApp and retrieve them later if needed:

"So, (laughs) you know that the children play on our phones... with WhatsApp, you can delete all the messages. Because if I don't want kids to read what's in my inbox, I will just... delete

all... the conversations. And with WhatsApp you can delete the conversations... and [later]... you can get all the media back.” [P1]

P1 highlighted that she used this particular feature to limit what information her children could access when she shared her phone with them, reinstating messages later once she was alone with her phone again. This functionality offers a unique benefit for 4MNetwork, as the group’s activities focus on mentoring women living with HIV on their pregnancy journeys and beyond. Being able to easily delete and reinstate group messages allowed P1 to control what information her children could access on her phone, as it was a device shared between multiple users. Being able to do so without disrupting the information available to other members of the group was voiced as being a key benefit of WhatsApp for P1, as she was able to customise what information was available on her device easily; this being her choice alone.

This participant also described customising her ‘status’ message¹²⁸ within her WhatsApp profile for both personal and professional reasons:

“Updating the status [in your profile]... I like that... On WhatsApp, that's a good thing. Because you can update your status, you can share... you can have your personal thoughts... like little things you can do, which you cannot do in a text message. Like on the WhatsApp (status), you have some items and write your personal statement, or your values or your thoughts, and then, every day for 24 hours, you can change your status. So, if you want to compete for something, or highlight something like International Women's Day, you can. You can do that...which you can't just do with a phone number or in a text message.” [P1]

She highlighted that having a ‘status’ was unique to some platforms, allowing her to communicate additional personal or professional

¹²⁸ A ‘status’ is a short message that accompanies your name and image within a WhatsApp profile. This is visible to anyone you contact on WhatsApp alongside your contact details (e.g. phone number) and can be edited at any time.

information in a unique and enjoyable way. Whilst she spoke about enjoying this feature, she also noted that individual customisation meant that some profiles lacked information that she wanted to know about others:

“Sometimes you don't know whose number it is or who is who, and obviously, if you click on [their account] and go on their profile, it might [have]...a category there or a profile with their name. And if they don't, then it's none of your business.” [P1]

While P1 might prefer to have found identifying information, she also respected that others may not want to share such information within their profiles.

When describing mentoring others using WhatsApp, P2 explained why others may not wish to include some information within their profiles:

“If I'm mentoring, there is, you know, I would always ask... if you're comfortable with, you know, even, because on some thi[n]gs- like on WhatsApp, there's my [profile] picture...I'm not famous or anything, but even then, someone [other than the mentee] could see that picture and then think, “Oh, well, I've seen that [in relation to HIV]” you have to be quite careful with someone who really doesn't want to disclose their status, what you're sharing, and what links other people might make.” [P2]

The information within her profile could present a potential risk for her mentees, as it may unintentionally share information to others viewing the mentee's phone. This contrasts with P1's enjoyment in using her profile information as a means of expressing her personal or professional interests. The ability to customise profile information within WhatsApp allows for both of these experiences to co-exist equally, making what is displayed an individual choice.

6.4.2.3.2 Asynchronous schedules

Some of the participants raised the importance of being able to access and engage with the WhatsApp group when it suited their schedules. As described by P2:

“It's and it's not like... here {referring to the phone interview} because having a phone call at a fixed time... with WhatsApp I could come home now, I've be on shift all day... come home and my phone clicks online because I've got WiFi at home, and then there's WhatsApp messages. There's a distance in that way, but I kind of like that... you can choose the time when you want to look at messages.” [P2]

She enjoyed being able to access the group when she wanted to, rather than at a specific time. She further elaborated that *“text messages to each other... would feel more like an intrusion into other parts of my life, whereas the way that [WhatsApp] works [it's] more of a choice when and how and where [I review messages]”*. P2 preferred being able to limit when she would review the 4MNet WhatsApp group, feeling that this was less intrusive than text messaging because it allowed her to choose when the app would be available to use.

6.4.2.3.3 Missed connections

While the ability to use the platform in a way best suited to each individual user was viewed as positive by several of the participants, this also led to negative experiences. As expressed by P1:

“I posted once and nobody responded, which can be a bit hurtful (laughs). They could have been muted as well, on the other hand. It's the same that people will send in achievements, and sometimes people are responding, sometimes people are not responding.” [P1]

Because the 4MNet WhatsApp group serves dual professional and community functions, not receiving a response on her post hurt P1's feelings; she felt that she had been denied acknowledgement by the group. Whilst she explained that this was likely related to some members muting the group chat or being otherwise unable to engage with the group at the time, these combined factors helped create a situation where P1 felt she did not receive support from her peers within the group chat.

6.4.3 “We just keep it to what [it] is”: Establishing and Sustaining Feelings of Trust, Respect, and Community (SRQ3)

The final super-ordinate theme and its subthemes relate to how the WhatsApp group maintained the values of the 4M programme (see Fig. 29). Participants expressed how feelings of trust, respect, and community were established and sustained within the group, through purposeful choices about how the members engaged with each other.



Figure 29: 4MNet interview study super-ordinate theme and subthemes mapped in response to SRQ3.

6.4.3.1 Trust

6.4.3.1.1 Invite-only platform

P1 explained that the 4MNet WhatsApp group helped establish trust between members by making the membership invite-only: you need to be invited to join the group by an existing member in order to be

added. As described by P1: *“Obviously if you're in that group... then somebody... trusts [you]; it's a trusted group someone put you in”*. P1 felt that anyone added to the group could be trusted if they had the trust of one of the existing group members.

6.4.3.1.2 “Confidentiality about what gets shared”

This feeling of trust was sustained through mutual respect for individual confidentiality within the group. P6 expressed that whilst she was personally open about her HIV status, she believed that the 4MNetwork had established a feeling of ‘group trust’ in which all members knew that their confidentiality would be respected:

“I don't have any anxieties because I'm completely open about my HIV status. And I don't feel that I'm posting anything on there, which would be betraying any of my... confidentiality. But I can understand that for other women, obviously, there's always that sort of question mark about whether others are going to respect that confidentiality. But, you know... there is a group trust there that people will respect the confidentiality about what gets shared in the group.” [P6]

As the group operated as a support network for peer supporters, P6 believed it sustained feelings of trust by all members respecting each other’s confidentiality. This was understood as a core element of the 4MNetwork at large, which was established and maintained in the WhatsApp group through the professionalism of its members.

6.4.3.2 Respect

6.4.3.2.1 “We have strict, strict rules”

Several participants [P1, P2, P3, P5, P6] touched upon respect for each member’s time being a key factor and benefit of the 4MNet WhatsApp group. P1 noted that this respect was informed by the group’s rules of engagement: *“Because otherwise... we [would] have 100 messages... so people are good with it... [messages are] something work-related or something tangible-related... we have strict, strict rules.”* P1 and P2 both remarked that a set of rules

drafted by the group guided how the group engaged on the platform. P2 explained how the group had made this set of rules together, making a commitment to respect what each member wanted out of the platform:

“There were some people who were like..., if we're going to do this, don't send me blessings, don't send prayers, don't send angels, and don't send jokes and that. I think maybe because we set [the WhatsApp group] up after we had been together for a whole weekend there was a list of rules that you easily can just obey... I think maybe that's why we all stick with it. Actually, thinking about it, that was probably why. Because, you know, some people are very resistant to it and it's so we had to make sort of a promise that we weren't going to do that, so that if people had started [the group without rules it] probably would have... fallen apart, very quickly.” [P2]

P2 reflected that the group's ongoing commitment to following their rules on engagement helped support more members participating, and this 'promise' helped members 'stick with' their commitment to the rules over time. She noted that the rules had also been drafted collaboratively to be easy to 'obey', informed by a weekend of discussions between group members. These conversations allowed each member's voice and concerns to be respected and included within the rules.

6.4.3.2.2 “There's an etiquette to it”

The rules drafted by 4MNet members helped sustain the professionalism of the members' messages, such as when they were sent. This was referred to as “work etiquette” by P1: *“We are conscious of... what time you're posting... we take it proper, like you consider the work etiquette. Even if it's about professionalism, there's an etiquette to it”*. P6 expanded on this, explaining it had been a conscious choice to limit what times messages should be sent:

“We sort of explicitly agreed between us when we first linked up [on WhatsApp] that we were going to focus on...work predominantly, and that we're not going to share... favourite cat photos (laughs). We were trying to do our best to limit it to work times, so not [messaging] after 9pm in the evenings for

instance, or on weekends. So that there was sort of a reasonable kind of work time for sending and receiving stuff.”
[P6]

This sense of work etiquette, guided by the 4MNet’s rules, informed what content was shared and when it should be sent. This helped sustain a professional atmosphere in the group, noted by P5: “*with 4M [the WhatsApp group is] more like a professional platform, whereas my family and friends—it is not formal. It’s not as formal as... 4M*”. The professional etiquette and formality of the 4MNet WhatsApp group helped reinforce it as a purposeful and respectful platform for P5, P6, and P1.

6.4.3.2.3 “Nothing there is wasteful”

The professionalism of the WhatsApp group reinforced its value as a worthwhile use of time for members. P2 commented on how this professionalism was notably different from other HIV support groups that she was a member of on WhatsApp:

“There are other... HIV support groups that I belong to... but it’s not the same at all. There you get a lot of ‘oh I have blessings for you’ and ‘these pictures’ and a lot of... I don’t want to say it’s rubbish but, you know, but it’s wasting my time to look at that... I don’t know how they managed it with 4M, but no one does that; they managed to create some kind of magical boundary that no one wastes—nothing there is wasteful.” [P2]

The professionalism supported by 4MNet’s rules of engagement ensured that each message shared within the WhatsApp group was meaningful and thereby respectful of each member’s time. This environment led P2 to expect that “*if there’s something [new posted in the group] then it’s going to be worthwhile*”. Both P7 and P3 noted that they edited what they shared in respect of the focus of the group, P7 keeping messages “*purely professional*” and P3 highlighting that she would “*avoid sharing irrelevant things*”. P2, P7, and P3’s experiences highlight how respect for each other’s time has been successfully established and sustained within the WhatsApp

group through the initial drafting of group rules and members' ongoing commitment to them.

6.4.3.3 Community

6.4.3.3.1 Conversation and commitment

In addition to the rules themselves, 4MNet's values were established through the way the group chose to co-create the rules through conversation and commitment. Revisiting a section of P2's statement from the previous subsection:

"We set [the rules] up after we had been together for a whole weekend... we had a conversation about it and a commitment—if we were going to do it, in order for everyone to participate. You know, we didn't want anyone to drop out because of that." [P2]

This highlights how 4MNet's values of community informed how they chose to draft the group's rules of engagement. Whilst the rules themselves help support the ongoing professionalism of the group, values of community and care were also written into the initial rules through how they were drafted: together and in order for everyone to participate.

6.4.3.3.2 "We take care of each other"

Some of the participants expressed how 4MNet's value of togetherness are sustained through the caring and supportive feedback shared within the group, reflective of its underlying community. P1 described how positive feedback helped support a sense of community and care for others within the group:

"Some people are giving going to give talks and they're like, 'Yeah, yeah, so and so went for a talk here' or something - So there's a sense of celebration... We take care of each other, and we other understand each other. So when, I think, when it's work-related, why the group was connected, it will be welcome." [P1]

P2 also commented on how personal updates from individual members were generally considered worthwhile within the group:

“You know, if there's something then it's going to be worthwhile. If it's, if it's someone saying they're not feeling well that is still worthwhile because then we can all rally and say 'It's going to be okay'. And if it's someone celebrating, it's good news... it's a good connection.” [P2]

Both P1 and P2's voiced experiences emphasise a culture of caring and support within the group, with updates and their responses helping to sustain a sense of community between members. P2 went on to reflect on how this sense of community within the group had led her to feel more supported:

“Maybe [being involved in the 4M WhatsApp group hasn't changed] the way I've thought about myself, but the way that I've thought about others? Which in turn, is... in the way that I feel supported. I view myself as more supported. And I think that's because I would have viewed myself as supportive before, but I think being part of this group, it means that I'm... because I think I was not someone to reach out for support. So... and it, it doesn't feel like you're reaching out for support, it's just that you're sharing and then you'll receive support.” [P2]

For P2, the reciprocal culture of sharing and support had created an environment where she felt supported, without needing to explicitly ask for help. This highlights the ongoing value of community and care within the 4MNet programme, and its continued value for peer mentors: providing support for the supporters.

6.4.3.3.3 “Being a part of something”

Some of the participants described how being a part of the 4MNet WhatsApp group helped sustain their feeling of being a part of a community that is contributing to something important [P1, P6]. P1 described this as:

“Being part of a something that's forward moving... something that's active and ongoing and feels that it's already ahead of time or, you know, in motion. Like, forward. Forward, yeah.” [P1]

She felt continually reminded that she was a part of a larger community through her ongoing involvement with the group through WhatsApp, sustaining her feelings of being a part of something

forward moving. A sense of ongoing confirmation was also raised by P6, one of the PMTs for the group. P6 expressed how being continually connected to other members of the community via WhatsApp had reminded her of the dynamic work being done:

“[Being involved in the WhatsApp group has] enhanced my admiration for all of the women involved... because I knew that they were special anyway, but {laughs}, but this [has] kind of confirmed... how special they are. And... how many dynamic things they're doing, which is really great. And it's lovely... It feels quite a privilege to be part of the group.” [P6]

Both P1 and P6 shared feelings of being a part of a dynamic community, reinforced through their ongoing involvement with the WhatsApp group.

6.4.3.4 “We’ve learned how to...”

Lastly, some of the participants raised how the training provided by 4MNet through digital channels was connected to their sense of community within the group. As a professional network, the group often engaged in training or educational activities together, with P1 noting that *“with this group we've learned how to go on webinars... that was good... because otherwise I wouldn't have been able to know about it”*. Beyond offering professional training opportunities, some participants also expressed how the community of the group helped support members in their learning. For example, P2 described how an event during a webinar had been handled by the group:

“[In] another webinar... there was someone on video (chuckles) so suddenly you could see this person getting in [their] car... because we all support each other we don't want to be, you know, saying (yelling) “Turn it off!! Turn it off!! Come on, put it on mute!!”, you know? We want to listen, because you know they're going to work it out in their own time and... you don't want to put them off from never joining [again], because they're joining and they're learning how to use it... like now, I think on the last [webinar] we were all very successful and we all managed to mute it and no videos and, yeah. We were all there and that's what I mean about practice and just finding you own way and also not being... if you can't do something not being... judged badly for it... [but]

appreciated for your participation... it's important to... just be... guided gently and be accepted... for appearing in the middle of the screen (laughing).” [P2]

P2's description of how an accidental error was purposefully handled with care and respect demonstrates how the group's sense of community permeates their engagements with each other digitally and their support for each other's learning. 4MNet's value of community and care is sustained by the ongoing support members provide for each other, including giving others space to learn and make mistakes.

6.4.4 Reflective Analysis: Entwining Themes & Mapping Connections

The three themes from the 4MNet study presented in this chapter¹²⁹ interconnect at various points due to the complex entwining of community and professional factors, inherent to any form of peer support. These have been mapped (see Fig. 30 below) through an additional stage of reflective analysis, highlighting how 4MNet has addressed concerns raised by members through their designed approach to using WhatsApp.

¹²⁹ (1) 4MNet's WhatsApp group as a professional community; (2) 4MNet's use of WhatsApp balancing benefits and concerns of accessibility, adaption, and customisation factors; and (3) how 4MNet's values of trust, respect, and community are established and sustained within the WhatsApp group.

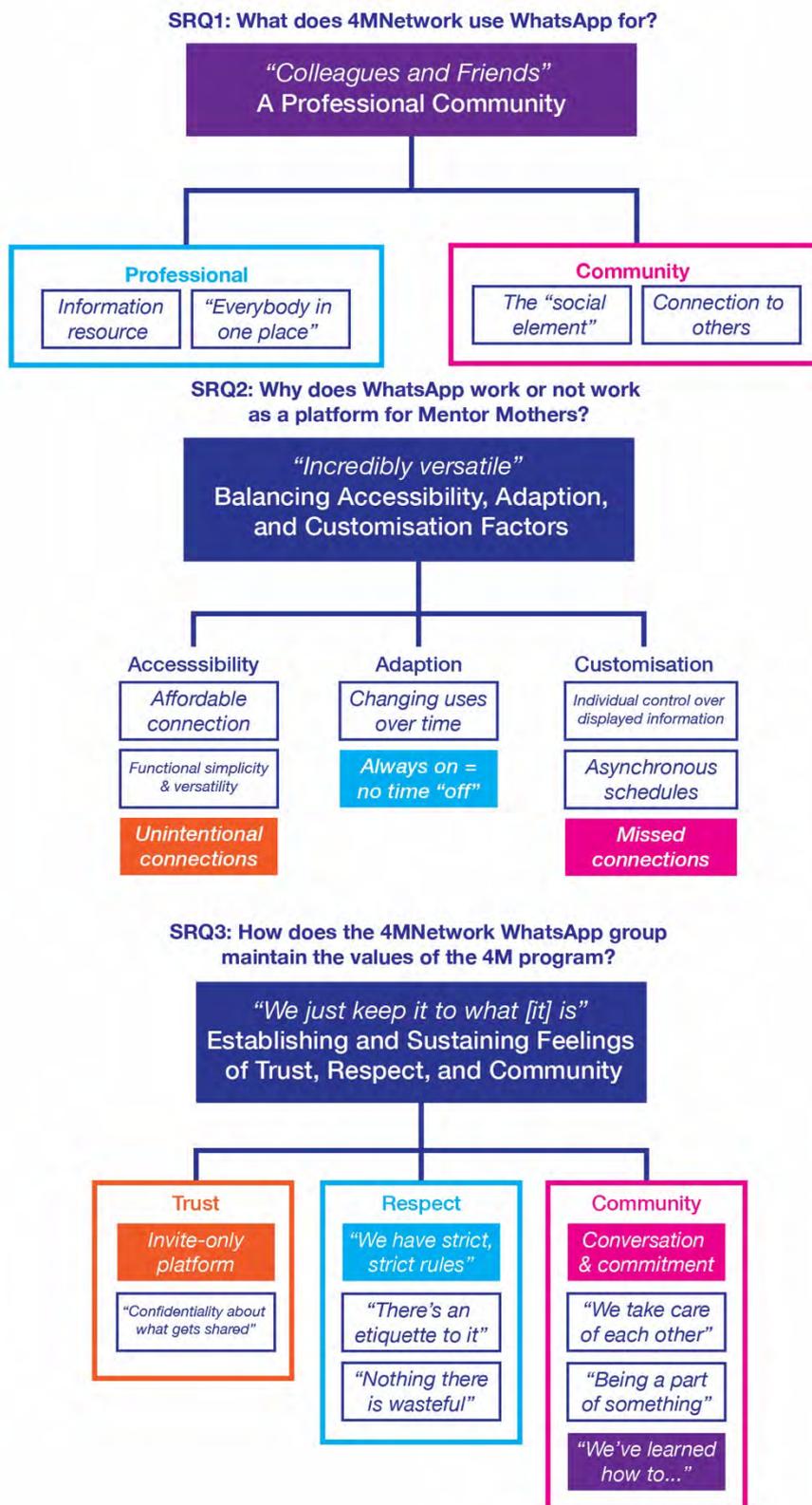


Figure 30: Thematic mapping of all super-ordinate themes and subthemes within the 4MNet interview study.

Firstly, as a professional resource the 4MNet WhatsApp group provided a space for colleagues to share information, give support to one another, and learn new skills. Using WhatsApp allowed service delivery to be flexible and adaptable to changing individual and/or group needs over time. Whilst concerns were raised by P3 and P4 about how the group's positioning within WhatsApp could create additional professional responsibilities, this was mitigated, in part, by the group's rules of engagement. P1 and P2 described how these rules guide how the group is used, establishing and sustaining respect for each member's time through professional etiquette and meaningful communications. These rules appear to help balance concerns about the additional responsibilities, providing each member with a voice in how the group operates, and establishing shared understanding and trust.

Secondly, these rules were drafted by the members of 4MNet to ensure that everyone would feel confident and comfortable in using WhatsApp for group communications. These choices were founded in group conversations, and values of caring and communal support continue to be reported alongside the benefits of the group's primary professional focus. Ongoing positive communications, support, and celebration of each other's work sustained a meaningful sense of community and connections. This includes the importance of feeling connected to others whenever needed. The one member not participating in the group (P4) reflected that she would likely have greater feelings of connection to other members if she engaged with the WhatsApp group. Whilst members are able to customise their individual use of WhatsApp to align with their needs and schedules, this customisation may also unintentionally lead to some messages going unnoticed, creating negative experiences for some (such as P1). Whilst not perfect, this sense of community and support was exhibited in several aspects of the group's professional work,

including how members learning new digital skills were given gentle guidance to motivate them to continue developing their abilities.

Lastly, WhatsApp was voiced as being a valuable tool by the majority of the participants for its low cost of access, wide availability of legacy device support, and its familiarity (of the platform and its functionalities) to users, making it an easy choice for the group to use. However, this relative ease of use also presented concerns for some participants. These concerns included potential financial burden (data storage and ongoing access); and unintentional information sharing. Concerns about how WhatsApp could allow for unintentional information sharing through profile information was also raised. This consideration is contrasted with the enjoyment of using WhatsApp's profile and status functions as a space for personal and professional expression. The polarity between these two experiences reflects the importance of information sharing for women living with HIV when faced with potential discrimination. The 4MNet WhatsApp group helped establish and sustain trust between members around information sharing through (1) operating it as an invite-only group and (2) sustaining group trust by keeping shared information confidential. As the 4MNet WhatsApp group operates as a platform for peer supporters rather than mentees, this helped maintain a sense of trust and security that also allowed for individuals to express themselves as they chose.

6.5 Reflections on Praxis

Although I had previously worked with NAT through a design praxis, this study was the first doctoral study that I conducted in full collaboration (being involved from study design through to study publication) alongside an organisation that exclusively represents

women living with HIV. Whilst administratively complicated¹³⁰, this was an invaluable experience. Being able to collaborate, discuss, and receive feedback on study analyses and written outputs gave me a new perspective on how the experiences of women living with HIV could be framed differently to how I'd previously seen them presented academically. A pivotal moment in my understanding took place when I read the following comment from Alice Welbourn (Fig. 31), one of 4MNet PMT's involved with the project, made on a section about the concept of stigma within a drafted paper based on the work presented in this chapter:

Alice

I'm afraid I find this whole focus on stigma quite depressing and stigmatizing in itself. This is why I have continued to feel oppressed by the title of 'The Stigma Index' project. When we are traumatized, our default position for us all is fight, flight, or freeze and I feel this narrative feeds into this default position. Instead if we talk about Seeking Safety and ensuring safety as the starting point – and that many of us women living with HIV feel this especially strongly, then we can explain how lack of self-esteem and external attitudes and practices are in the way and the peer support is addressing this.... So we are starting with identifying the solution and how to find a way to it, rather than focusing on the problem and dissecting that at length. I know that the identification of the problem is what scientific research always does – but this is another challenge we have with research – that it always focuses on the negative rather than starting with a positive vision and thinking how to reach it. The former just raises our cortisol levels (which in turn suppresses our immune system), whilst the latter is much more creative and raises our serotonin level – and feelings of well-being.... If I am feeling optimistic I can look forward positively. But the ongoing discussion of stigma I feel throws me back to a time of feeling very low and traumatized, which doesn't feel good.

Figure 31: Comment from Alice Welbourn, a 4MNet PMT co-author on a drafted manuscript about the study. Highlighting by Author, included with permission from Alice Welbourn.

To me this comment encapsulates the need for representation of women living with HIV within research, not merely as subject but also as author, and highlights the importance of a strength and assets-

¹³⁰ As the members of 4MNet who collaborated with me on this study are not located in Newcastle-upon-Tyne, this study was conducted entirely digitally (over the phone, or using skype, email, or WhatsApp) from initial planning through to study publication; my co-authors from the project and I met for the first time at the conference we presented the study's poster at in London, months after the study had been completed. This involved many emails, schedules, and updates, creating additional administrative work and complexity.

based approaches in research. As a woman not living with HIV it had not been obvious to me that continually refining understanding of what HIV-related stigma is (and how it affects the use of technology for women living with HIV) was not necessarily acting to address it. In order for change to happen, change had to occur in what was *happening* within the lives of those experiencing HIV-related stigma, not in how the phenomena was understood. This comment refined my approach to my doctoral work and thesis, refocusing my attention on identifying and moving towards possible futures rather than analysing phenomena alone: “*starting with a positive vision and thinking how to reach it*”. This kind of learning would not have been possible without a community-based and collaborative approach to conducting research in this space; this comment likely would not have arisen if the collaborator had not been involved in writing the manuscript. This experience and feedback refined my approach to develop understanding whilst also co-creating meaningful outputs alongside my collaborators through my design/research praxes: co-creating all outputs, paper or product, together.

6.6 Summary

This study highlights key insights about how digital peer support services may be meaningfully designed by and for women living with HIV. An analysis of the voiced experiences of 4MNet members highlighted how the 4MNet community addressed members’ concerns about using WhatsApp as their main channel for group communication; they designed their use of it to enact and retain valued aspects for individual members. Their various configurations of the WhatsApp features, combined with rules of engagement, reflected their care for each other’s continual, but flexible, involvement, their collective trust in mutual confidentiality, professional respect, and supportive social community. Members established shared rules and chose a platform that could afford

accessibility, adaptability, and customisation features, in order to satisfy both individual and collective needs.

Despite these designed responses, some concerns were expressed in relation to how use of the platform could place financial burden on individual users, allow for accidental information sharing, and potentially increase the stress of professional responsibilities. These concerns reflect how everyday individual contexts might be considered or excluded within the design of digital services. The decision to use WhatsApp was made together, and a set of rules drafted through conversation to allow for individual concerns to be addressed through the way the group engages on the platform. 4MNet has designed their use of WhatsApp to suit these voiced needs; the platform itself also allowing for individual members to adapt and customise their use of the tool further without disrupting or contradicting this shared use agreement.

These insights respond to RQ1 and RQ2 of my doctoral project: identifying factors that impact the use of digital technologies within the daily lives of women living with HIV; and highlighting 4MNet as a specific case study of how women living with HIV have specifically developed and used digital technologies in response to these factors. The process of this collaborative research study also informed my approach to RQ3 in the subsequent research study within this doctoral work: co-creating a publication to be used in service delivery with women living with HIV.

In the following chapter I take inspiration from 4MNet's approach to "*starting with a positive vision and thinking how to reach it*" through design research. This study will report on the collaborative process of co-creating a publication for new referrals to an in-person peer support group for women living with HIV in Newcastle-upon-Tyne.

This publication provides form to abstract knowledge about what peer support represents for service users in their journey of living with HIV, and what they feel is valuable to communicate to those newly-referred who may become clients. This marked a return to my work with my original community partner, Blue Sky Trust (BST), and provides a worked example of CBCDP.

7 “It’s all about the journey”: Co-Creating a Zine for New Referrals to an HIV Peer Support Service alongside Women living with HIV

7.1 Introduction

My previous doctoral studies inspired me to co-create a design artefact that could shape the form of future design works involving digital HIV peer support spaces. Firstly, my work with 4MNetwork reported in the previous chapter had raised the importance of contextual knowledge and values within digital peer support services for women living with HIV. Second, my work with National AIDS Trust (Chapter 5) highlighted how Making activities could result in useful, tangible representations of such values to guide collaborative digital projects. These insights prompted me to return to BST, and to approach their staff members and service users with the invitation to co-create a tangible representation of the peer support journey that participants had described in my first study (Chapter 4). I aspired to engage in dialogue with the BST women’s group members through a design praxis to illuminate further abstract knowledge about their experiences of peer support, co-creating an example (artefact) of how this meaning-making could be materially communicated. Through conversations with BST staff, it was agreed that this collaborative project would take the shape of a co-created zine publication to be given to women who are newly referred to BST’s services, in order to express the strengths that current women’s

group members felt they had developed through their journeys within the group.

Zines are self-published documents, an alternative media (Atton, 1999) with a limited print run; their maker(s) decide upon the content, production process(es), and distribution of the publication¹³¹ (Duncombe, 1997). In the 1980s, zine-making was adopted by some who were living with HIV/AIDS as a means to self-expression, community building, and knowledge exchange or connection between those who felt unrepresented, ignored, or hidden from mainstream representation or activism (Brouwer, 2005; Long, 2000). In recent years, the zine format has been appropriated for academic research dissemination involving underrepresented groups¹³², including people living with HIV. Examples such as the 'The Criminalization of HIV in Canada: Experiences of People Living with HIV' zine, which facilitated self-publishing of academic research reports (McClelland, 2019), utilise zines to provide a medium for HIV information dissemination and advocacy. Design practitioners have also used zine making in co-design processes to inform the creation of informational resources. For example, Canadian design agency And Also Too co-designed an informational resource (a booklet) about infant feeding with mothers living with HIV, using co-creative design methods to inform the narrative structure and content for the resource (And Also Too, 2015).

My previous studies explore the contexts in which digital tools and services have been developed and used. These studies evidenced

¹³¹ The historical origins of zine-making can be traced to other historical methods of self-publishing, such as pamphleteering, and connected to digitally mediated forms of self-publication such as blogs (Duncombe, 1997).

¹³² Pamphleteering has been similarly revitalised as an academic dissemination medium to promote public discussion, such as the 'Urban Pamphleteer' series founded by Professor Ben Campkin and Dr Rebecca Ross (Urban Pamphleteer, 2021).

personal and interpersonal experiences rather than exploring the visual design space of HIV social support services. A previous review of Experience-based Co-design research studies in Health (Donetto et al., 2014) highlighted that work within this discourse often lack clarity about how insights may be operationalised in the design of actual healthcare services¹³³. Previous insights, such as the importance of “warm tones” and a spirit of professional community, can appear to be more connected to those providing a service than inherit to a particular tool—limiting understanding as to how the *designed form* of digital tools and services may support or restrict communication of these valued aspects of service provision.

Guided by a Fourth Wave HCI approach (Frauenberger, 2019) (2.2.3), where people and the material world are entwined in meaning making practice, it is important to consider how digital tools and services *themselves* might actively affect the perception of their users. I chose to use zine making in a co-creative method to illuminate how experiences of the peer support journey were perceived by women living with HIV, and what language, visual metaphors, and narrative structures were expressed to communicate these experiences. I chose a sequential art medium (a zine booklet) as it could be read similarly to how one might ‘flip through’ the screens of an app’s onboarding process, providing inspiration for how an interaction designer might approach crafting the onboarding experience for the user of a digital HIV peer support tool or service (5.3.2.1)(Carroll, 2000; Durrant et al., 2018).

This Fourth Wave approach (Frauenberger, 2019) views digital technologies as a *medium* for social and communicative intervention

¹³³ Donetto et al (2014) suggest that this may be due to these works not involving design practitioners and recommend that service designers should be involved within Experience-based Co-Design studies in Health.

rather than as a tool to accomplish objective tasks (Löwgren & Reimer, 2013). Focusing on perception instead of objective tasks means understanding the person using a digital artefact as an audience rather than a user—the view of Communication Design praxes¹³⁴. My previous studies focused on the viewer as a user, and how the usage and usability of digital tools and services is affected by various contextual factors. This current study builds on this to consider the *perception* of the viewer as an audience member, focusing on *what* is important to relay to those being newly introduced to an HIV peer support service and *how* the associated meanings and values may be visually communicated.

Understanding how to visually communicate meaning to the user of digital tools or services is important for the design of any digital artefact. In HCI Design discourse (i.e. Interaction Design), Visual Communication Design (e.g., Graphic Design) is often considered in terms of usability (e.g., wayfinding) or in relation to contextual use by specific user demographics (e.g., cultural tailoring) rather than how it affects a viewer’s perception of meaning of beliefs (Sharp et al., 2019). However, my studies to date have highlighted how contextual factors that affect digital interactions are also often related to *beliefs*—especially negative beliefs in connection to HIV-related stigma. Concerns about losing control over one’s HIV information has been voiced in relation to negative lived experiences or expectations of discrimination¹³⁵; These concerns are especially important for

¹³⁴ Communication Design discourse has highlighted the general distinction between ‘audience’ and ‘user’ projects: audience-focused projects often focus on viewer *perception* (e.g. their impression of a logo) while user-focused projects typically focus on viewer *performance* (e.g. their ability to use signage to locate a destination) (Nini, 2006).

¹³⁵ This has been repeatedly raised within the previously described works through the ongoing privacy considerations to control the sharing of HIV information, whether this be concerns about being connected to peers on public social media platforms (4.5.2.2); others seeing a user access HIV information (5.3.2.2); or others recognising an image of a peer mentor on a mentee’s mobile phone (6.4.2.3.1).

those newly accessing social support services (such as peer support). These beliefs are neither objective usability concerns (as stigma is a subjective phenomenon¹³⁶) or homogenous (as stigma is socially mediated and people living with HIV are diverse), and thus do not fit easily into existing Interaction Design discourse on Visual Communication Design.

Considerations for how a viewer's beliefs may be affected by Design has been previously raised within the HCI field through Agnostic Participatory Design (Björgvinsson et al., 2012) and Interaction Design (Löwgren & Reimer, 2013) discourses. However, these works have focused on the designer's role in affecting beliefs via participatory processes of making or interactive collaborative media (e.g., social media) rather than digital artefacts as active agents for meaning making in their own right¹³⁷. When considering how interactions with digital artefacts might affect beliefs about HIV, there is extremely limited guidance or inspiration to draw upon. National standards for HIV peer support services advocate for using digital technologies in addition to in-person peer support provision (Positively UK, 2017) but do not provide guidance on best digital engagement practices or platforms. I had learned through my previous collaborations that introductions to HIV peer support services are often made individually, with representatives or mentors engaging with a potential service user one-on-one. What if this introduction were to be mediated digitally? If negative beliefs about HIV could be positively affected by involvement in peer support, how

¹³⁶ HIV-related stigma is a subjective, socially shared belief (Goffman, 1990), and these concerns had been created and enforced by participants being in the world.

¹³⁷ Frauenberger (2019) referring to this as socio-materiality, or the entangled agencies of both people and things within knowledge production or meaning making, within his definition of the Fourth Wave HCI approach.

could digital tools and services be designed to help support the introduction to this journey?

Given my methodological approach to the PhD, it was also important to critically reflect on how I, a designer who practices without experience of living with HIV, would be co-creating a visual language with women who did. Discourse on using participatory visual methods (PVMs) (Switzer, 2018) and conducting Arts-based Health Research (ABHR) (Boydell et al., 2012) underscore the ethical and methodological challenges of co-creative projects in marginalised health contexts – given the uneven power relationships between collaborators. Previous Art and Design-led research involving HIV has addressed these challenges through critically-informed collaborative or co-design endeavours, including by positioning Design as a translational agent between interdisciplinary collaborators (Wizinsky, 2019); using an iterative design process as means to sense-check meaning between ‘expert’ designers and audience (Bennett et al., 2006); and using visual methods to create tangible artefacts for participants to reflect upon their own experiences with (Switzer et al., 2020). In using an ABHR method (zine-making) for HCI Design research, it was methodologically important that this study also show how much influence participants desired from a professional designer within design and production processes.

This study’s research questions (SRQs) were guided by Fourth Wave HCI (Frauenberger, 2019) perspectives. I wanted to explore how a co-created artefact could communicate beliefs deemed important to peer support introductions:

(SRQ1) How are experiences of the peer support journey conceptualised by women living with HIV, and what language,

visual metaphors, and narrative structures are expressed to communicate this journey?

(SRQ2) How much influence do participants desire from a professional designer within the zine design and production process?

I also addressed the third main research question for my PhD (RQ3): *What approaches can inform design praxes involving Digital Health tools and services within stigmatised health contexts?* This study addresses this question in two ways, through (1) the use of design artefacts for Interaction Design research involving stigmatising beliefs; and (2) the co-design process for co-creating such artefacts.

7.1.1 Context of Engagement

I returned to the offices of BST in Newcastle-upon-Tyne, planning to conduct a design-led study of how the journey within peer support for women living with HIV could be visually communicated. I had prepared three proposals for collaborative design works, which could serve as fundraising products or activities after the life of the project. These included live performances, an art exhibit, and a zine publication. I purposefully chose to limit the involvement of digital technologies within these ideas, as the previous focus group had highlighted concerns about using digital technologies outside of the group (4.5.2.2).

BST staff members and I decided that co-creating a zine with the women's group would be the most appropriate design work. Staff suggested that creating a zine may interest the women's peer support group based on their previous collaborative art works and recommended that the zine be made on their current topic of discussion within the group: new strengths established through on one's journey with the peer support group. Rather than being used for fundraising, we decided that the zine would be given to women

newly referred to BST during their initial meeting(s) with staff members. New referrals often meet a member of BST staff privately before deciding to engage with a larger peer group; the zine would offer a way for the voices of the group to be shared within these initial private meetings. We decided that several copies of the zine and its digital files would be given to BST upon study completion, and each participant would receive a copy of the zine and be remunerated with a £10 shopping voucher. The peer support group coordinator and I then met to plan out and schedule the workshops.

7.2 Method

7.2.1 Study Design

The original study protocol, devised in dialogue with my supervisors Abigail Durrant and Lynne Coventry, divided research activities across three sessions. The first session would introduce the project, its aims, and ethical consent procedure to the women's group. This session would also introduce the concept of what a zine was and how to make one. I would prepare a small zine (to show how one could be made), notebook, and pencil for each prospective participant, so that they could begin thinking about what strengths they had developed through their peer support journey prior to the first workshop (Fig. 32). I would also bring an assortment of zines from my personal collection to show various publication and visual styles for inspiration.

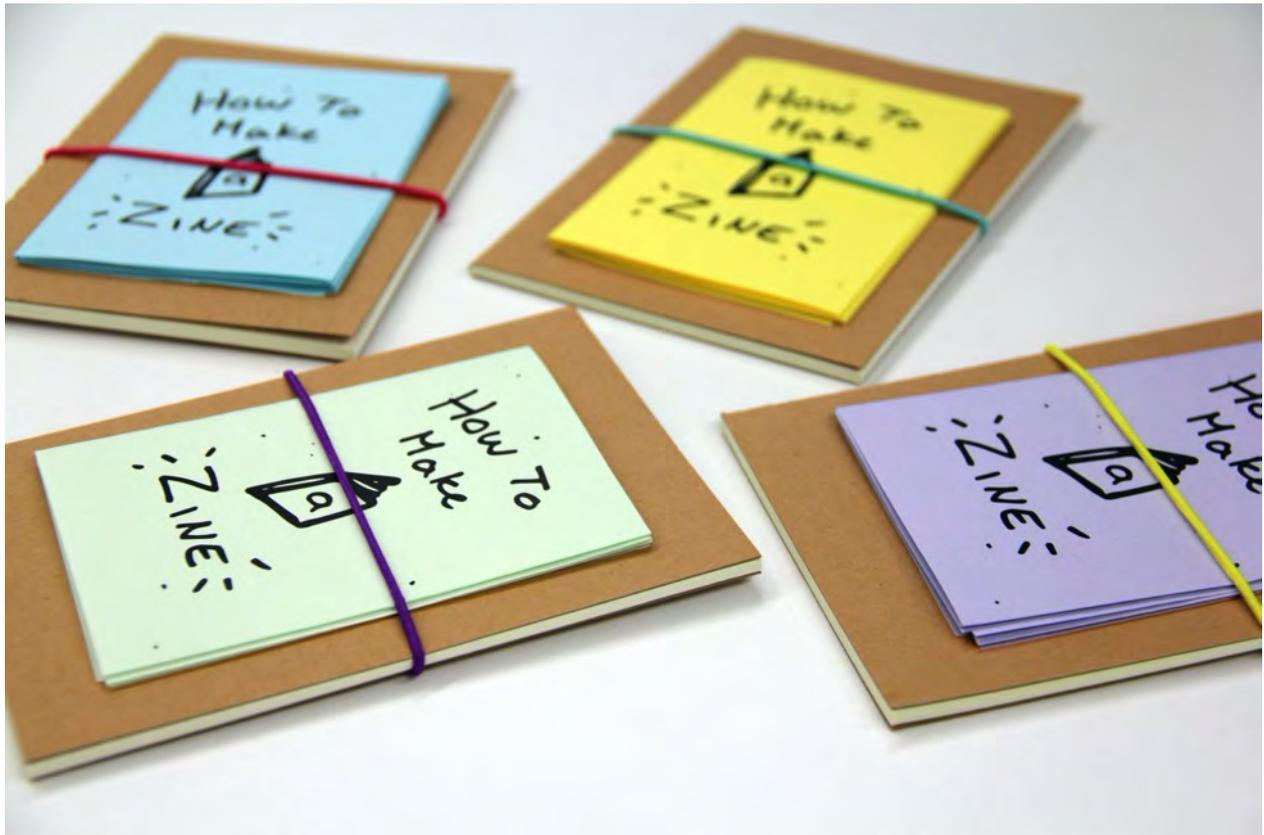


Figure 32: Four versions of the zine 'How to Make a Zine' and notebook set, given to each consenting participant during the first study session. Photo by Author.

The second session would begin with a brief introduction of the project, the day's activities, and an overview of the ethical consent procedure before completing consent forms with participants. The workshop would then start with the group describing various strengths they had built up or discovered through their journey within peer support; these being listed on a large piece of paper for review. Participants would then be given templates to complete an A5 page (or pages) for the zine (Fig. 33), basing their design on one of the strengths listed. Several media resources would be provided for zine making: a portable printer for printing personal photos; materials for drawing, painting, and writing; and magazines for collaging. At the end of the session each participant would present their respective zine pages to the group, describing what strength they chose and

how they decided to present it. Presentations would be audio recorded and transcribed to support analysis of the final zine.

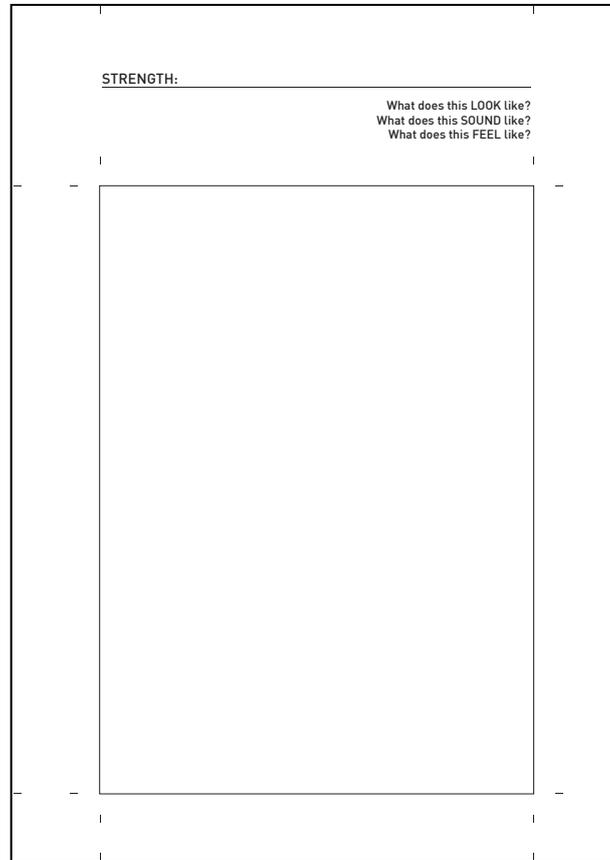


Figure 33: Zine page template with crop lines to indicate the final A5 page size.

Photo by Author.

The third session would begin with a brief introduction of the project and activities before talking through the ethical consent procedure and completing consent forms with any new participants. The workshop would start with a bookbinding activity, which I would prepare materials for and lead (Fig. 34). After this we would arrange the zine pages on a large table and have a group discussion about what order the pages should go in, what the zine's cover should be, and how the final zine should be bound. I would again bring in several zines from my personal collection as examples of printing

and binding styles. This discussion would be audio-recorded and transcribed to support analysis of the final zine.



Figure 34: A booklet prototype made to illustrate the final product of the bookbinding activity. Photo by Author.

After the pages had been made and the publication ordering and style decided upon, I would prepare the interior pages for the zine before binding them in line with the group's decisions. A physical copy of the zine would be made for each participant; at least 24 copies for Blue Sky Trust; and several for my own archive of the project¹³⁸. Following production each participant would be remunerated with a £10 shopping voucher and a copy of the final zine. BST would also be given digital files of the final zine, so it could be reproduced.

¹³⁸ Exact numbers would depend on the size and materials of the zine.

7.2.2 Ethical Considerations

The study protocol was reviewed by the departmental Ethics Committee at Northumbria University and approved on 17 October 2019¹³⁹. Informed consent was granted by participants, at the start of their first session with the project. Workshops were scheduled within existing peer support sessions and communication materials simplified¹⁴⁰, to prevent unintentional information sharing. The topic of ‘strengths’ was also chosen to avoid triggering traumatic feelings for participants and to keep discussions ‘future-focused’ (6.5). Using a variety of craft, paper-based media for the project and oral discussions for the project kept research activities accessible for all participants, addressing issues around written language raised previously (4.6). Establishing the purpose of the proposed zine output with staff at BST and participants prior to the start of the study helped address the ethical and methodological considerations of using an art-based method with a marginalised community, by planning for a meaningful outcome of study activities.

7.3 Procedure

The protocol was adapted to run five sessions instead of three, followed by a series of informal production meetings. This extension to the method was approved by BST after study commencement due to participant interest and the extra time needed to include additional design activities within the study.

¹³⁹ This was done through an amendment to my initial ethics application (Appendix F.1).

¹⁴⁰ Printed communication materials, such as information sheets, were simplified within this study in response to the challenges encountered within my previous study with the same group, as described within (4.6).

1.1.1 Session One

The introductory session (session one) of the study took place on 15 October 2019. The study was well received by the women's group members, with participants expressing that they were excited about working on a larger creative project together¹⁴¹ and looking forward to getting started the following week. Notebooks and zine sets (Fig. 32) were distributed to several prospective participants¹⁴², who enjoyed the set's colourful packaging and appeared excited to make a zine together in the following weeks.

1.1.2 Session Two

The second session took place the following week (on 22 October 2019). I arrived early to help the group coordinator and another BST volunteer set up tables and chairs within the main BST meeting room, laying out various art supplies (e.g., markers, paints, scissors, glue), a photo printer, and several piles of magazines (for collaging). Six participants consented to participate in the study and two BST volunteers joined the activities to assist participants.

We began with a group discussion of strengths gained through one's journey with the peer support group; I listed the participants' responses on a large sheet of paper so that everyone could see what had been said previously (Fig. 35). Participant responses are also listed below in Table 5. This generative activity continued until participants expressed that they were satisfied with the list.

¹⁴¹ The women's group at BST had previously been involved in other creative works as a group, including knitting hats and blankets for charitable donations and

¹⁴² Participant information was not collected for this session as it was not a part of the formal study. I have included it as a 'session' to reflect the overall project timeline.

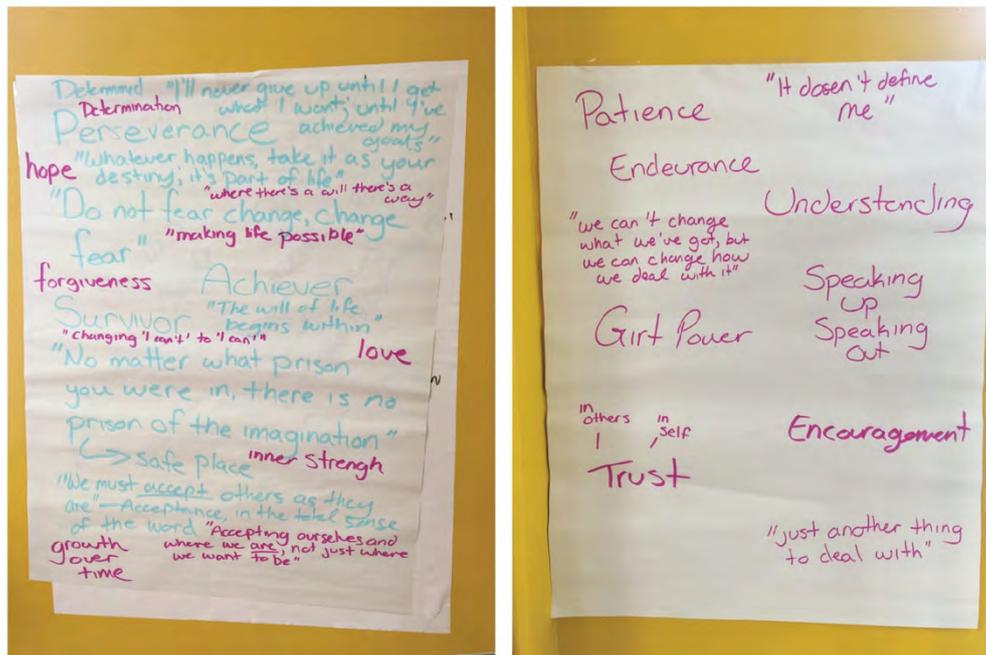


Figure 35: Pictures of the 'strengths' listed by participants during session two of the zine-making study. Listed 'strengths' are also written out in Table 5.

Table 5: 'Strengths' listed by participants during session two of the zine-making study, presented in no particular order.

Determined	"making life possible"	Achiever	"It doesn't define me"
Determination	Forgiveness	inner strength	Girl Power
"I'll never give up until I get what I want; until I've achieved my goals"	"No matter what prison you were in, there is no prison of the imagination" (a safe place)	"We must <u>accept</u> others as they are"— "Acceptance in the total sense of the word"	Understanding: "we can't change what we've got, but we can change how we deal with it"
Hope	Survivor	growth over time	Speaking up speaking out
"Whatever happened, take it as your destiny; it's part of life"	"The will of life begins within"	"Accepting ourselves and were we <u>are</u> , not just where we want to be"	Trust: in others; in self
"where there's a will there's a way"	"Changing 'I can't' to 'I can'"	Patience	Encouragement
"do not fear change, change fear"	Love	Endurance	"just another thing to deal with"

Zine template pages were handed out once the group was satisfied with the listed responses. I then introduced the various types of media that could be used to create the pages and the zines that I had brought as examples and inspiration. Over the next hour the women created their pages, choosing to focus on making collages. Participants flipped through the magazines to find and cut out pictures; the volunteers and I assisting in finding specific images. By the end of the session most women had not started to create their pages, as they had needed the time to find appropriate images from within the stacks of magazines. It was decided that the next session would also focus on creating pages for the zine, and that the number of sessions would be increased to facilitate the additional time needed. Participants collected and stored their images in plastic files, to be kept with the art supplies until the following week.

1.1.3 Session Three

Session three took place the following week (on 29 October 2019). I again arrived early to help set up tables, chairs, and supplies for zine making. Three new participants joined the sessions after being introduced to the project and informed of the ethical consent procedure. It was a school holiday, so a few young children had attended with study participants (n=8; five from the previous session and three new). The children were entertained by one of the volunteers and a BST staff member on the other side of the meeting room, whilst the women completed their zine pages. The other volunteer and I moved around the group, assisting participants with their pages by helping to source additional images, find supplies, and help with spelling. By the end of the session, a few women had completed their pages, so it was decided the following week's session would be divided into two parts: the first half to finish the remaining pages and the second for participants to present their pages and discuss ordering them in the zine.

1.1.4 Session Four

Session four took place in the following week (on 5 November 2019). The women arrived after the volunteers and I had finished setting up the room for the final zine page making session. Fewer women attended this week (n=5; all from previous sessions) than previously due to other commitments. Participants who had not completed their pages previously, spent the first 45 minutes finishing them up whilst the others relaxed.

Once everyone had completed their pages, the group gathered to present their pages, explaining which images they had chosen to use and why. Whilst this discussion was originally intended to take place separately from the page ordering, once all the completed pages were on the table participants instinctively began to rearrange them. Individual page presentations unfolded naturally between discussions about ordering, additional content to be added, and what the cover of the zine should be, the topics of discussion being led by participants, volunteers, and myself at various points. At the end of the discussion it was decided that I would prepare mock-ups of what the interior zine pages would look like for the following session, during which some additional content (decided upon through the group discussion) would be created by participants.

Following this session, I created a mock-up of the final zine. This included scanning and editing the completed collages for print quality; creating several illustrations of roses blooming; printing and trimming the interior pages as two-page spreads; creating cover prototypes; and preparing several materials options for the final zine.

1.1.5 Session Five

The final formal project session took place a week later (on 12 November 2019). Three participants from the previous session attended. Activities began with a bookbinding activity; I guided participants in making a small canvas booklet¹⁴³ (Fig. 34). After participants had completed their booklets and the table was cleared, I showed the mock-up of the zine that I had made, getting the participants' feedback on colours, image placement, and the cover prototypes to inform the final version (Fig. 36). Participants also chose specific materials for the zine to be made from and requested a ribbon bookmark to be added. After discussing the edits, the participants started to make the additional content for the zine that had been decided upon in session four.



Figure 36: Rough versions of the interior zine pages with notes by participants in session five. Photo by Author.

Two participants painted abstract artworks to represent their emotional journey before and after their involvement with peer support, providing oral artist statements. I recorded their oral

¹⁴³ This activity was adapted from an online DIY tutorial (Sea Lemon, 2017), making a booklet with square canvas board covers and several interior pages using a meander accordion fold (one sheet of paper). This binding style was chosen for its simplicity and creativity, offering a new way to think of how a booklet could be bound.

descriptions by hand, to be added to the zine later beside the paintings. The other participant created additional labels on a label maker. Once everyone had finished their pieces, we discussed how the production of the zine would be completed after the winter holiday season. I was invited to drop into the women's weekly meeting informally at any point during this process to clarify design choices and update the group on the zine's production.

1.1.6 Production Sessions

The zines were finalised and produced over the next two months (Fig. 37). I attended the women's group informally several times over this period to ask opinions on elements of the zine (e.g., ribbon bookmark colour), to keep everyone informed of the production process, and to attend several celebration events for various members. In addition to serving pragmatic and social functions, production sessions also operated as an analytic Making activity, explicating the meaning behind visual design choices (e.g., why this colour or ribbon?) and illuminating how much influence was desired by an 'expert' designer within this stage of the co-creative process.



Figure 37: The final zine production process. Covers and pages were printed, trimmed, and glued before being creased by hand and awl punched in preparation for hand stitching the binding. Photo by Author.

In total I produced 70 copies of the final zine by hand (Fig. 38). The zines were completed and distributed to BST on 25 February 2020: nine copies were given to participants during the women's group weekly meeting, along with a £10 shopping voucher; and 31 copies were given to BST staff members for use in early discussions with new referrals. I kept 30 copies of the zine for archival and exhibition purposes, with the understanding that BST could request additional copies as needed. I also sent the final digital files of the zine to BST, should they wish to produce additional copies themselves.



Figure 38: Photo of the final zine, 'The Rose of Love'. Photo by Author.

1.2 Participants

Nine women attending the peer support group participated in the study over the course of the zine-making project. Participants were recruited using internal convenience sampling over several weeks, by engaging those who attended the weekly peer support women's group sessions. I was advised by staff members that this would reduce the burden of their participation.

I chose not to collect participant demographic information as I had established a general demographic profile for the women's group in a previous study (see 4.3.2.1). Collecting demographic data in the previous study had taken additional time and focus, and I wanted to

avoid adding undue stress or highlighting divisions between participant/researcher at the start of a co-creative project.

1.3 Research Data Types

As a practice-based research method, this zine-making study collected several types of research data. This included: **artefact data** (any artefacts explicitly produced to be included within the zine, such as zine template pages, or the final zine itself); **design process data** (physical artefacts produced through Making activities, such as sketches or prototypes); and **descriptive data** (audio recordings, transcripts, field notes and artist statements). These data were collected throughout the study during session and production activities, always with informed consent.

Physical artefacts (artefact and design process data) were photographed or scanned before being organised within a study-specific folder on a secure hard drive (kept in a locked drawer). All physical artefacts were kept in a separate locked drawer, except for the paintings produced for the zine (which were returned to their creators after being photographed). A physical copy of the final zine was reviewed in conjunction with the digital versions of other physical artefacts for analysis.

I collected descriptive data using an audio recorder (session four discussion) or via hand-written, pseudonymised notes (artist statements and field notes). Audio recordings were then transcribed and pseudonymised by me before deleting the original audio recordings. Transcripts were stored on a secure hard drive (kept in a locked drawer). Artist statements were typed and saved digitally from notepaper; recycled after transcription. I wrote field notes by hand during and after study sessions to capture my observations and reflections. These were collected within a notebook series that I

created throughout my doctoral projects. These notes were re-read and reflected upon during study analysis to provide additional observational detail to my accounts of study sessions.

7.4 Analysis

This study used a novel arts-based design method (zine making) to conduct practice-based research (Gray & Malins, 2017) through the co-creation of a design artefact (a zine). Analysis of this research process and product reflects the 'artful' and 'rigorous' values of this qualitative research approach (Coffey & Atkinson, 1996). This led me to use a novel visual analytic process informed by Interpretive Phenomenology (Smith et al., 2009) and Visual Anthropology (Collier, 2004). This analytic process is summarised in Fig. 39 and described in further detail below (and within Appendix F.3).

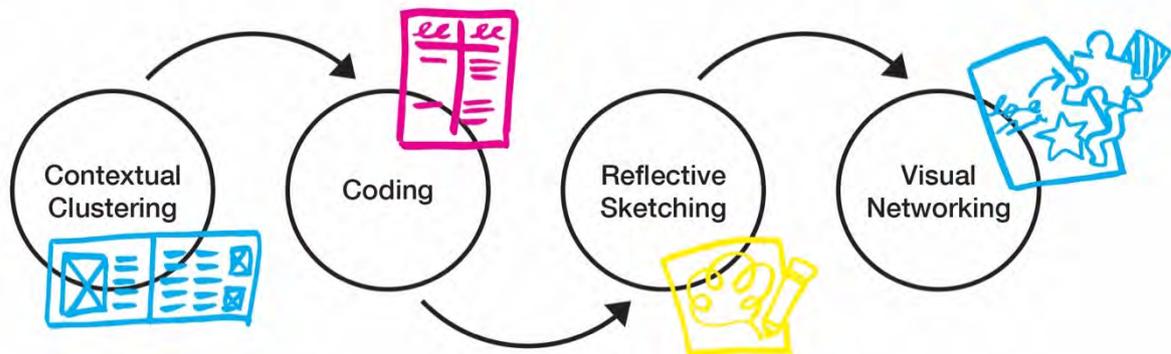


Figure 39: Overview of the novel visual analytic process used within the zine-making study. Image by Author.

Contextual Clustering

An audio recording of the discussion from session four was transcribed, pseudonymised, and reviewed in conjunction with the zine artefact. These materials were then contextually clustered in a separate document to juxtapose participant interpretations (transcript excerpts) beside images of the page(s) being described (Fig. 40; see

an interconnected process (or network), rather than through a hierarchy of distinct themes. Distinct experiences harmonised with each other in relation to each woman's subjective journey and visuals at different points, highlighting the importance of presenting them in connection with each other and the plurality of these connections for each participant. Inspired by the visual narrative representations of research outcomes presented in research work led by women living with HIV (e.g., ICW, 2004; Orza et al., 2014)¹⁴⁶, I then began sketching a visual representation of this network, using the visual language of the illuminated experiences to depict their entwinement (Fig. 41). This approach allowed for distinct experiences to be represented as individual elements with abstract interconnections, reflecting how I made sense of the data.

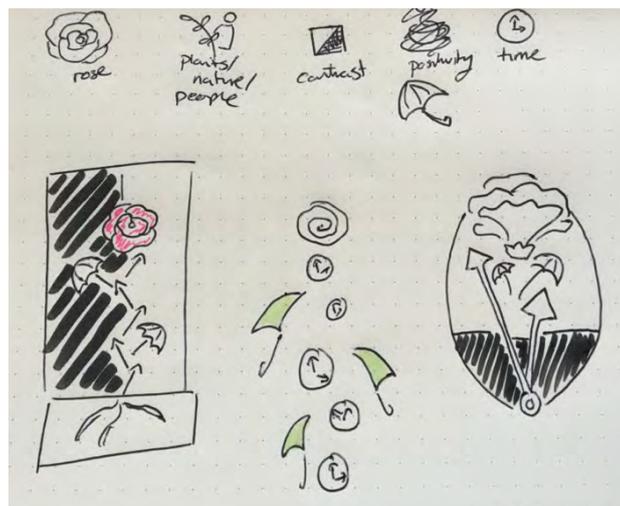


Figure 41: Reflective sketches using icons of the five visual metaphors. Photo by Author.

¹⁴⁶ These cited research work use visual metaphors of a 'building a safe house on firm group' (Orza et al., 2014) and a 'fruit bearing tree' (ICW, 2004) respectively to communicate research findings visually.

Visual Network

I chose to illustrate this visualised network of experiences using same materials as the zine artefact (collaged magazine images, illustrated roses) to reflect its material language. Guided by the taxonomy, I collected and collaged various images to reflect the identified experiences. These collages were scanned and further collaged digitally (Fig. 42). Reflecting on these drafts I then refined my collage and added additional sketched visuals (clock faces, hands as roots) to improve clarity between the distinct visual representations (presented in Fig. 43 within the upcoming Findings section).



Figure 42: Drafted version of digital collages using magazine images (left) and sketched assets (right). Images by Author.

7.5 Findings

Findings from this study are presented in two subsections, highlighting their relation to the two study research questions (SRQs). Insights into how the experience of the peer support journey was communicated through language, visual metaphors, and narrative structures (SRQ1) will be described first, followed by insights into how much influence from a professional designer was desired within the zine design and production process (SRQ2). These insights are organised under the 'Content (SRQ1)' and 'Process (SRQ2)' subheadings, respectively.

The design of this study meant that participants had various levels of involvement within the zine design and production processes. Participants and BST staff members are referred to using monikers related to their work within the zine's design and production process in the following section. A brief overview of these is listed below in Table 6. I have chosen to only give monikers to the participant's whose work or input is directly referenced within this section for clarity.

Table 6: A list of the monikers used to refer to collaborators in the zine-making process within the following section

Moniker	Description
Author	Myself, PI of this study.
Art volunteer	The co-ordinator of the women's peer support group at BST who had previous experience as an art teacher. She helped facilitate all workshop activities, including discussions about the zine design and production, and drew the three-panel comic of a flower being grown used on the first spread of the zine.
Maker	A participant who made all the green labels used within the zine in addition to two zine pages.
Poet	A participant who wrote the poems that open and close the zine, in addition to a zine page
Artist	A participant who painted one of the abstract art works for the zine, in addition to a zine page and some calligraphy
Painter	A participant who painted one of the abstract art works for the zine, in addition to some calligraphy.
Lady	A participant who participated in the editorial discussion.
Mama	A participant who also worked at BST. She created several zine pages but was unable to attend the discussion sessions due to maternity leave.

7.5.1 Content (SRQ1)

Analysis of study materials (zine artefact, transcripts, research notes) illuminated five experiences that use distinct narrative structures, language, and visual metaphors to express the peer support journey. A taxonomy of these experiences is presented below in Table 7.

Table 7: Table presenting a taxonomy of the illuminated experience categories and their affiliated visual representations.

Experience	Description	Representation
“It starts off rough and ends up beautiful”: The blooming rose as personal growth	The peer support journey as an unfolding process of positive personal growth	Visual metaphor of a red rose blooming
“Do not fear change, change fear”: Reframing moving forward	The importance of acceptance and resilience in starting and moving forward within the peer support journey	Images of nature and people juxtaposed with positive sentiments and phrases describing a hopeful and resilient progression through life
“All I could see was black all the time, and that’s what I felt”: Expressing negative experiences	Focusing on the change from negative to positive experiences rather than explicating negative events	Contrasting pairs of poetry and abstract artwork to shown change from negative to positive
“Opening up... starting to lift”: Growth through positive experiences	The value of receiving and providing forms of care (e.g., love, joy) within the peer support journey	Direct representation of positive experiences or values (e.g. food as food)
“All about patience and time”: clock faces and the importance of temporality	The importance and value of peer support as a temporal space for healing and growth	Visual metaphor of a clock face

These experiences were described as entwined within individual journeys of peer support, expressing the journey as a plurality of *interconnected and ongoing processes* rather than a generalised *linear progression*. These insights illuminate a process in which the overall experience is greater than the sum of its parts, or, as phrased by the Painter, "*it's all about the journey,*" rather than the destination. In response to this entwinement, I represent the interconnected network of these experiences using their distinct visual languages and metaphors below (Fig. 43). The individual experiences are further described in the following subsections.

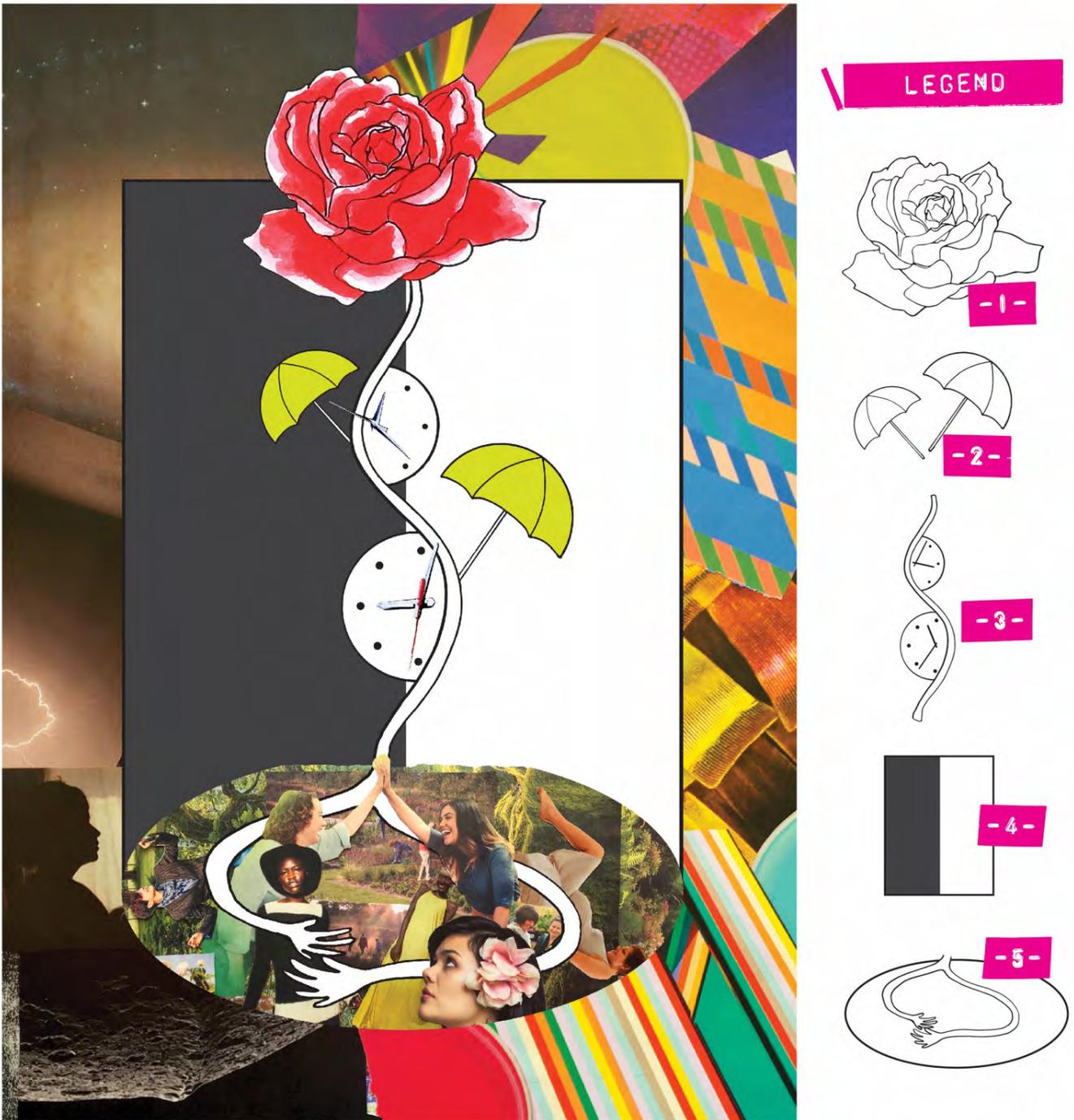


Figure 43: Collaged network map of the five narratives that emerged as part of the peer support journey, shown using their respective visual metaphors.

Image credit: Author.

7.5.1.1 *“It starts off rough and ends up beautiful”*: the blooming rose as personal growth

The primary narrative of the zine emerged, representing the growth and change experienced by participants through their peer support journeys. The narrative of growth and change was expressed by the visual metaphor of a red rose blooming; this process unfolding as the reader flips through the zine pages (the rose starting as a bud on the first spread and resulting in a fully bloomed flower on the last). This visual metaphor was inspired by the collection of strengths that the Maker had written out using a label maker (Fig. 44) and the subsequent discussion they prompted between those attending session four (Maker, Poet, Artist, Painter, Lady, Art volunteer, and I). These strengths and the related discussion about the labels would later inform the title of the zine, ‘The Rose of Love’.



Figure 44: Cover of 'The Rose of Love' zine, depicted beside a transcript describing the various labels included on the cover. Photo by Author.

This visual metaphor was decided upon following a group discussion prompted by the Maker's presentation (Fig. 44). A request to add a blooming flower to the front cover (along with the Maker's labelled strengths) was made by the Poet, Artist, and Painter, which quickly evolved into including the visual metaphor of a flower blooming throughout the zine:

POET: Yeah... [adding] like... a [plant] bud. Like we wanted (participants agree); y'know, like a bud...

ARTIST: yeah, like the sea, like a river...

POET: yeah, it's all, like that; and at the end of the book, it's [the bud] all open up

AUTHOR: oh; the little flower bud [is opening]?

POET: yeah, yeah

This brief exchange illuminated how the metaphor of 'blooming' was understood by the Poet, Artist, and Painter to represent 'growing,' moving from one state to another. This idea was then developed further by the Artist, Maker, and Poet, who clarified that they wanted an image of a flower blooming to be in the centre of the front cover, like a previous layout example I had presented. I sketched a rough example of what this could look like in response (Fig. 45) to clarify my understanding, which was approved by the present participants:

AUTHOR: And then adding some sort of... Like this is going to be very poorly drawn (drawing an example of a rose layout with the labels), but like a little... (drawing)... like a bud?

POET: Yeah! [...] And then on each page, a leaf opens up

ART VOLUNTEER: Oh! That's clever to do, through the book... (participants all "ahh!" happily)

POET: And as we get to the end [of the zine], it's just a beautiful flower

ARTIST: Yes! Yes! So nice... (participants make agreement sounds) Good idea...

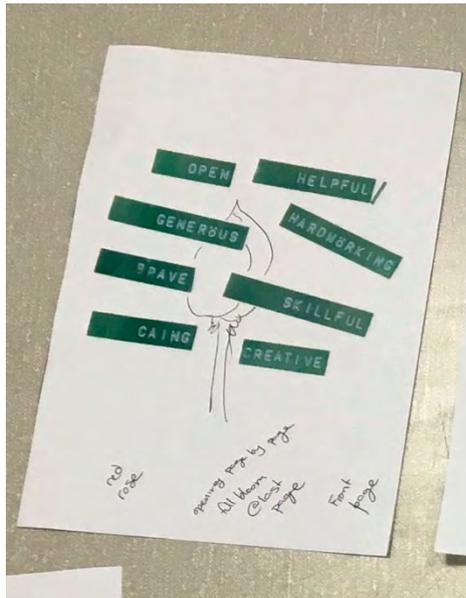


Figure 45: Cover sketch made by author, showing a rose bud with Maker's labels.

Photo by Author.

I offered to illustrate these images, beginning with a flower as a bud and finishing with it in full bloom at the end of the zine: “So *it*—each page has got a, a flower with an extra leaf that’s opened up” [Poet] (see Fig. 46). When clarifying if the cover should have a flower bud (to represent the beginning) or a flower in bloom, an exchange between the Poet, Art volunteer, and Painter explicated the flower blooming as a metaphor for growth:

AUTHOR: do you want the cover to then have an open flower (participants “mm!” in agreement), or do you think like the back page...

POET: yeah – like the back page has a flower that has opened up. So, each page it opens up, until it gets to the end and it’s in full bloom.

AUTHOR: yeah – that’ll be nice.

POET: each page is another... it opens, yeah...

ART VOLUNTEER: the growing... as a lovely – that, that’ll carry the book through (participants “mmm” in agreement)

PAINTER: it’s a beautiful metaphor isn’t it?

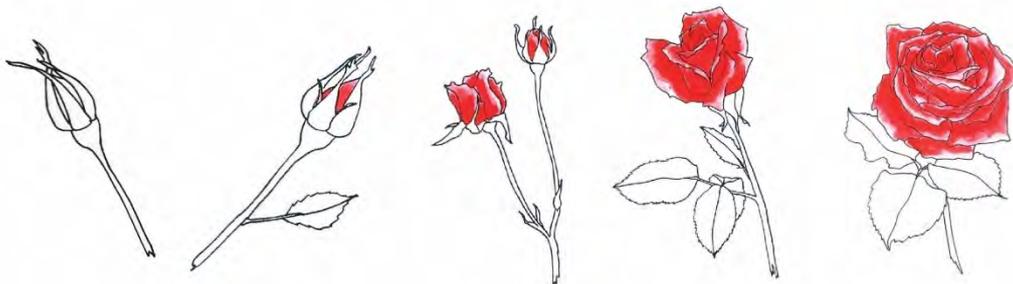


Figure 46: Illustrations of a rose blooming made for the zine. Illustrations by Author.

Participants all endorsed the visual metaphor of the blooming flower as growth, as explicated within this exchange. The Maker later expanded on this, describing that the bloomed flower as representing “[that] at the end... we succeed... we’ve conquered”. Through this unfolding dialogue I understood that the blooming flower represented how each woman’s peer support journey had helped her ‘grow’ various strengths, such as those labelled by the Maker; these strengths supporting her journey of personal growth from one state to another.

The visual appearance of the flower was then defined quickly, prompted by my requests for more guidance on the illustrations I would be making. Responses were led by the Painter, Poet, and Artist, their feedback unanimously agreed upon by the other attending participants:

AUTHOR: do you guys have a particular type of flower [in mind]? Like a rose or a daisy or... um... I don’t know, an iris? Or sunflower?

PAINTER: I was thinking about maybe a rose?

POET: (agreeing strongly) Rose. Yeah, rose. (participants make agreement noises)

AUTHOR: what kind of rose would you like?

ARTIST: I like... (various participants say “red”, make agreement noises) red roses (chuckles and laughter, as everyone has agreed so quickly)

Session participants quickly agreed on a sketched, red rose as visual. The colour red was later further specified by the Artist as “a *bright red colour, and vibrant,*” but was never discussed in relation to its symbolism for HIV. The importance of colour was later expanded on during the discussion about the style of the red rose illustrations, led by the Art volunteer while I took notes about participant feedback on my rough sketches of the front cover:

ART VOLUNTEER: (to the participants) do you like it drawn like that (referring to my sketches) or?

POET: yeah; I think it looks good like that, where it's between the words, yeah.

ART VOLUNTEER: so would you like it, just drawn, and then, with a picture of a red rose at the end? How would you like it [shown]? ...Do you want it drawn, like that?

AUTHOR: Like sketched, or painted, or [as a] photo?

POET: Ummm... I like drawn—just rough, y'know, because it starts off rough and then it ends up beautiful. (AUTHOR: yeah!)

ART VOLUNTEER: and if it's the same style all the way through, (POET: yeah) it'll lead you through—you'll recognise it, as the same image changing, until the end, when you can have the rose blooming in colour at the end.

POET: yeah

AUTHOR: that'll be nice

ART VOLUNTEER: that'll be lovely won't it! (participants make agreement noises)

This discussion, led by the Art volunteer and Poet, illuminated further insight into my understanding of the blooming visual metaphor and how it should be depicted. A hand drawn, sketch-like style (“*just rough*”) was chosen for the rose illustrations (rather than a more polished painting or photo of a rose) to reflect this visual metaphor of personal growth: “*starts off rough then ends up beautiful*” [Poet]. Furthermore, the sketched style allowed for the vibrant red petals to contrast against the greyscale flower bud, enriching the metaphor with further meaning. Some participants raised how their lives had changed for the better since their involvement with the peer support

group during zine design and production activities, and the evolution of the rose illustrations (from simple line drawings to vibrant watercolours) was designed to express this experience of personal transformation.

7.5.1.2 “Do not fear change, change fear”: Reframing Moving Forward

Several of the zine pages used language and imagery expressing a narrative of ‘moving forward’ with one’s life towards a positive future living with HIV. This narrative acknowledged negative experiences without focusing on them, which I have defined as themes of Acceptance and Resilience. These were illuminated through reflection on the final zine artefact (Table 8) and participant description. These sentiments were often communicated through written or collaged text of words or phrases, often paired with images of nature and/or people (Fig. 47).

Table 8: Words and phrases used within zine pages to express Acceptance and Resilience

Acceptance	‘We can’t change what we’ve got but we can change how we deal with it’; ‘if you are coming to this world, if you reach a certain point there is no turning back’; ‘open your mind’
Resilience	‘Endurance’, ‘Survivor’; ‘I survived because the fire inside of me burned brighter than the fire around me!’; ‘she was Brave and Strong and Broken all at once’, ‘I’ll never give up until I get what I want; until I’ve

	<p>achieved my goals'; 'Life is a shipwreck but we must not forget to sing in the lifeboats'; 'do not fear change, change fear'</p>
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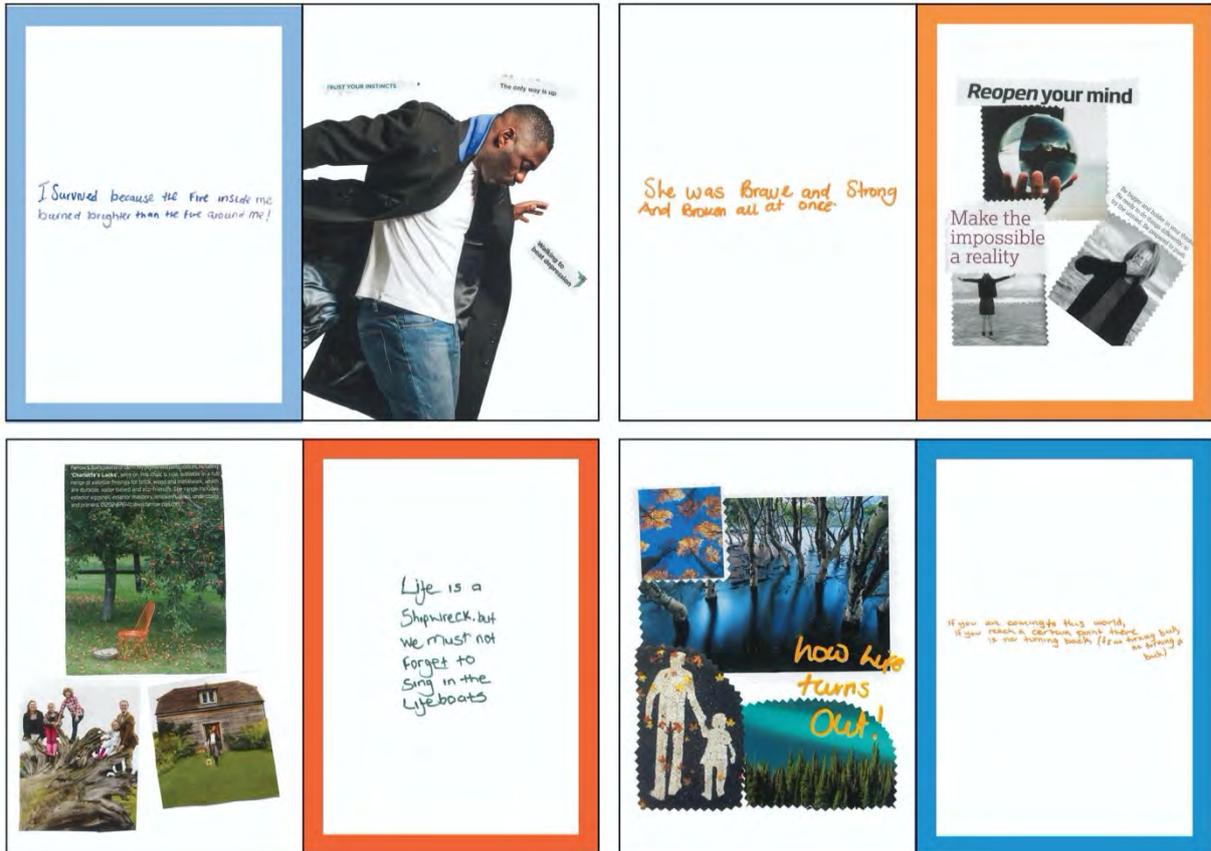


Figure 47: Zine pages using collaging text with images of people and nature that express sentiments of Acceptance and Resilience. Photos by Author.

Participants raised the importance of Acceptance in starting a peer support journey when discussing a zine page made by Mama, who had participated in an earlier workshop session (Fig. 48).

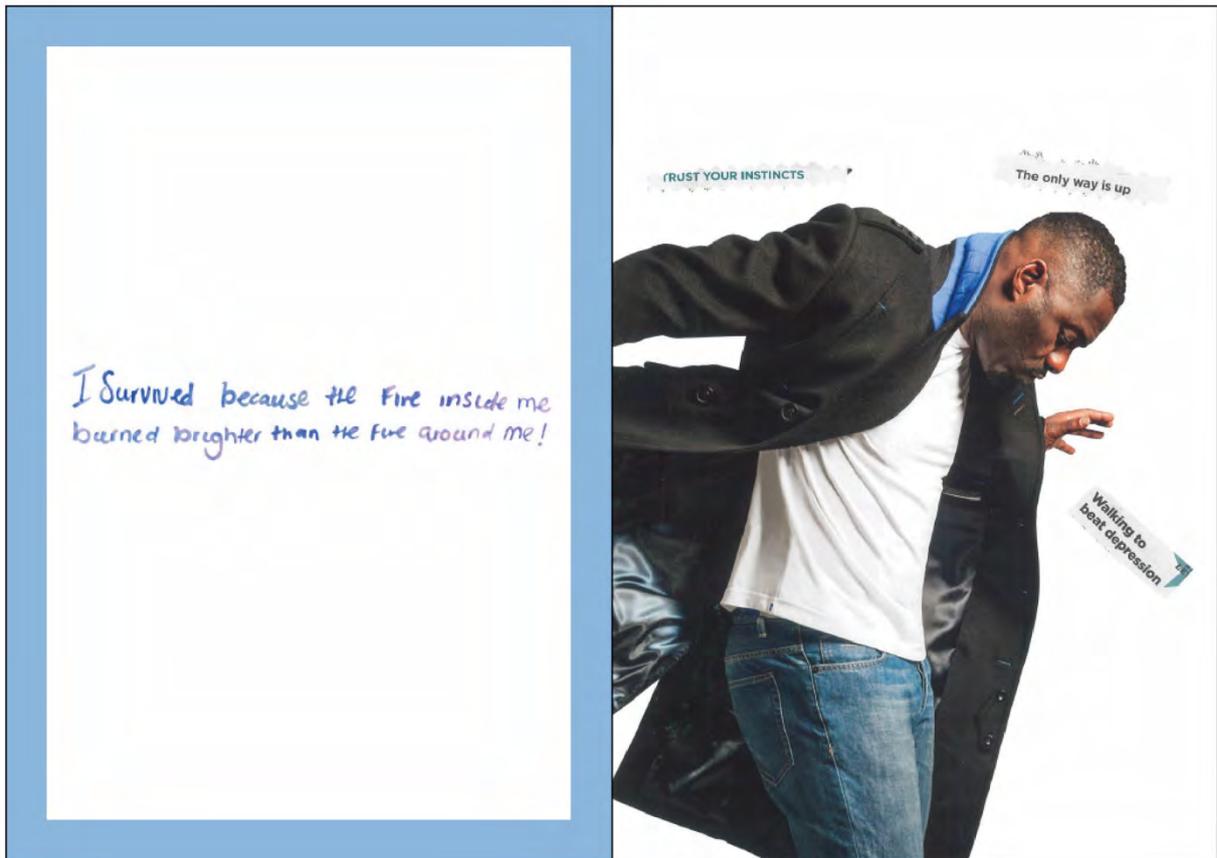


Figure 48: Zine pages made by Mama showing a man walking forward, surrounded by collaged phrases. Photo by Author.

This page was discussed during session four when I was reviewing completed zine pages with participants and discussing design choices. The Poet had highlighted the page on the table as one she liked, so I asked what she thought it represented. The page shows a man moving forward, which the Poet, Artist, Painter, and Art volunteer interpreted to express moving forward in one's life:

AUTHOR: ... Do you see that [this zine page is] more about... physically walking, or more so the idea of, kind of like moving forward?

POET: Yeah... like walking in your mind...

ARTIST: Moving forward

POET: Yeah, like moving forward, but in your mind is sort of like stuck isn't it, and you're trying to walk through it to get forward (ARTIST "mm" in agreement)

PAINTER: I think walking as well though, physically walking is good for ya. (participants agree vocally; AUTHOR: Yeah it's not bad)

PAINTER: Yeah, [going out to] the country, seeing, you know like we did in [a recent group field trip], and we had a lovely time didn't we? It was just so peaceful...

[...]

POET: Yeah... Put things [in perspective]

This discussion highlighted various ways that 'walking' could represent forward movement: processing thoughts and changing patterns of thoughts, moving forward in one's life, and walking outside providing perspective and peace. The Art volunteer then raised the idea of 'walking away' from things as another side of this concept, which the Poet and Painter interpreted as choosing not to face difficult things in one's life. This prompted the Poet to describe how moving forward had been difficult for her when she initially learned about her HIV diagnosis, as she had not wanted to face it:

ART VOLUNTEER: You walk away from things as well, don't you?

POET: Yeah; yeah you do.

PAINTER: Not healthy for ya...

POET: It makes it worse I think if you walk away from things you won't deal with it... I shut myself off for, at least three years ("mm" from other participants) ... I couldn't deal with it; I wouldn't even let anybody talk to me about... HIV or AIDS or anything like that... I just didn't want to know, I had it, and... that was it. It was there.

PAINTER: Just too scared to face it...

POET: I didn't want to face it! Well, I didn't want to hear about it, or nothing.

This utterance led some participants to reflect on how being involved with the peer support group had helped them accept their diagnoses by providing a space to share their experiences with each other. The Poet then related her own experience of this:

PAINTER: What's happened, yeah, you just need to get on with it haven't ya?

POET: It's the only thing you can do – you can only go forwards, you can't go backwards. I mean the past is in the past, the future hasn't come yet, [so] you've just got to deal with the present. [...] And, being here [at BST], we can talk to each other, and that, and I've found it helps, don't you?

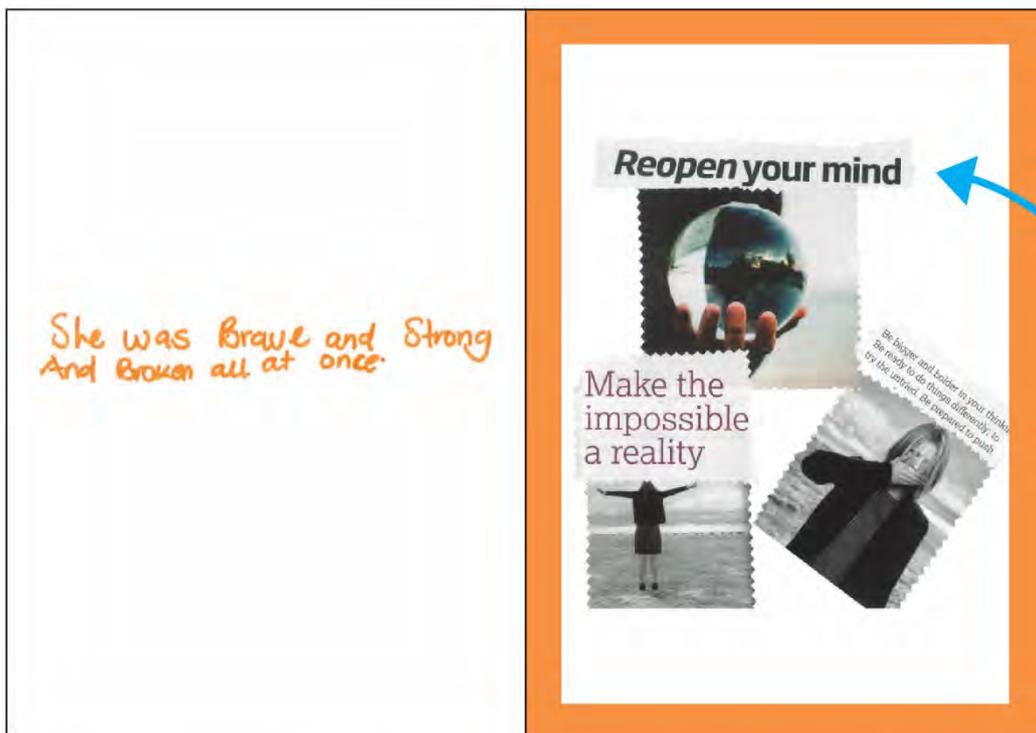
ARTIST: Oh, yeah... [POET: It helps so much]... [the] company... sharing... [with] beautiful persons [people]...

This discussion illuminated the disruption HIV had caused in the Poet's life, and how being involved with the peer support group had provided the support she needed to face this change. The zine page depicting the man walking forward (Fig. 48) was chosen to reflect this initial stage of peer support involvement, positioned as the first collage to be shown in the zine to represent the first step forward in a new referral's journey. Pages with similar encouragements to keep moving forward were also positioned in the middle and second half of the zine, including sentiments of *'life is a shipwreck, but don't forget to sing in the lifeboats'* (Resilience) and *'if you reach a certain point there is no turning back'* (Acceptance). These pages restate the importance of moving forward at different points in the zine using positive and peaceful imagery of nature and people beside encouraging language—repeatedly reinforcing the narrative of a positive future living with HIV.

This considered use of metaphor reflects and builds on how peer support services therapeutically impact ways of thinking: reframing conversations, which may have isolated or scared service users previously, towards a more positive, future-focused outlook. New referrals to BST (the intended viewers of the zine) may feel similarly to how the Poet had felt about living with HIV—not wanting to 'face' or 'deal' with it. These zine pages shift this introductory conversation from being about HIV to being about the life, happiness, and future of the viewer; acknowledging the difficulties that have been (and may be) realities but placing emphasis on how peer support can help the viewer move towards a more positive way of living. The visual

artefacts work to shape this communication, providing 'future-focused' visualisations reflecting the peace and connection to others that peer support provides through 'peaceful' imagery of nature and people (as relatable 'company'). This reframing reflects the experiences of peer support voiced by participants, serving as an example that others have been where the viewer is and have moved forward to better things (so the viewer can too). In this way the visual artefact may impact how the viewer frames HIV within their lives, easing their introduction to peer support services.

When discussing these zine pages further I asked participants how a zine about strengths could connect with those newly referred to the group, who may have similar difficulties. The Painter related her experience to the zine page depicting 'She was Brave and Strong and Broken all at once' (Fig. 49, below), stating "*When you're first diagnosed you feel all [of] them feelings*". Reflecting further on this page, participants highlighted the importance of raising these negative experiences within the zine to help support new referrals in accepting and moving past them; the Painter explaining "*[I]t's not turning back [to return to where we were], it's that we're changing from where we've been*". Participants said they felt that the narrative focus should be on how Acceptance and Resilience could help support a journey of *change* rather than focusing on specific negative challenges that a new referral may be experiencing. This informed my understanding of how narratives of Acceptance and Resilience within the peer support journey may be communicated visually: images and sentiments of a positive life continuing with others that acknowledges negative experiences as a reality, not focus, serving as testimony that change is possible.



POET: So [it's] not negative—you're got to deal with them; you've got to come to terms with them {PARTICIPANTS: 'yeah'}

ARTIST: Doing that, if [you] reopen your mind (referring to the zine page), doing that

AUTHOR: Oh yeah... [like] 'no turning back, no turning back'? 'How life turns out?' (referencing another zine pages)? {PARTICIPANTS: 'yeah'}

PAINTER: Yeah, it's not turning back [to return to where we were], it's that we're changing from where we've been, yeah...

Figure 49: 'She was Brave and Strong and Broken all at once' zine page and discussion; annotation in blue added by Author. Image by Author.

Narratives of 'moving forward' towards a more positive future were voiced in the group discussion and within several zine pages, which I further defined with themes of Acceptance and Resilience during analysis. These sentiments are expressed using text paired with images of people and nature—collages depicting examples of life continuing to exist onwards into the future, made by women who have been where the viewer may be. The combination of supportive

language and visual metaphors involving acceptance and resilience communicate a vision of peer support as an ongoing journey towards a better future; a future that won't be better because of the lack of obstacles, but instead bettered through one's acceptance of what is, resilience towards what will be, and the support provided by the group to help each other create the future(s) they desire.

7.5.1.3 “All I could see was black all the time, and that’s what I felt”: Expressing negative experiences

The severity of some negative experiences that the women had faced before joining the peer support group was raised whilst participants reflected on how their journeys had represented a personal change or transformation. When discussing if pages should be added to the zine to reflect such negative past experiences, which may be the present reality for those newly referred to BST (who would be the zine's audience), the Poet shared how her late diagnosis had led to a period of severe depression:

“The emptiness. I always... said myself I was toxic. That’s how I felt when... because I, I wasn’t diagnosed with... HIV, I had... extremely late diagnosed with AIDS. And, they only gave me two weeks to live, so... it was really really hard, y’ know, trying to... deal with that... I was suicidal. I just couldn’t cope with it. I ju- I don’t know—they say I’ve got it [HIV], from blood, but they don’t know when. And my last blood transfusion was in (pause, thinking).. 1998, and that’s when they said I... contracted the AIDS. But, because it lays dormant for... over eleven years, so... and I was fit as a fiddle, and I just woke up one day and I was really, really ill. And I just went down ill and they said... it was because I was celiac... and because I had bowel cancer, I had, lymphoma I [was told I had]... every disease going... but they didn’t test me for [HIV] because I was a middle-age white woman. And they wouldn’t test me... [...] the only way I could see out [back then] was to kill myself. Because I could see... (pause) I could see, I could see no light—all I could see was black all the time, and that’s all I felt. Black all the time.” [Poet]

The Painter responded to this by talking about how her partner's artwork has similarly expressed 'black' feelings earlier in his journey of living with HIV:

"[My partner] has gone through these sort of... stages as well, with his paintings... lots of them are very dark, because he's got HIV as well... They're starting to come, come out a bit now—he's painting with... brighter [colours] and more brighter things, and lighter things, but that's how he was in his head."
[Painter]

Rather than describe or depict these events in detail, it was decided that the zine would instead focus on how peer support had represented a journey from negative to positive experiences ("a feeling of [moving] out kind of thing..." [Painter]); building on the therapeutic 'moving forward' narrative described in the previous subsection (7.5.1.2).

The decision to use abstract paintings and poems was made during a discussion about how to acknowledge previous negative experiences without focusing on them. Different ways of visually expressing 'moving forward' from negative experiences were discussed, with the Art volunteer proposing using abstract paintings to echo the visual metaphor of contrasting colours the Poet and Painter previously described:

ART VOLUNTEER: I wonder... could you do a little painting on a canvas here, you know when we did the art class, and we did sort of abstract [painting], on a canvas, could you do a painting on a little canvas, but with all dark colours—dark blue, dark black, just all dark colours (ARTIST: yes), and... what about putting the [negative] words sort of in, in-between... (PAINTER: yeah...) or around it, or something?

ARTIST: I don't understand you [what she was saying]. Explain [to me] better; sorry.

ART VOLUNTEER: we're trying to, maybe visualise some of these difficult words, some of these negative words, (ARTIST: yes...) like emptiness, toxic, broken...

ARTIST: with colours?

Art volunteer: well I'm wondering if, yeah, instead of taking photos, what about colours? Like black...

MAKER: Blue...

ARTIST: Dark grey...

MAKER: light for light; light colour...

ART VOLUNTEER: Well I think this page, would it be dark? Because for negative [feelings], what comes into your head?

MAKER: black, brown

ARTIST: grey...

ART VOLUNTEER: maybe an abstract based on those colours, like you know those [Painter] you do those... in fact [Artist] you could do that as well couldn't you?

ARTIST: I can...

In this conversation, the Art volunteer drew upon the previous discussion and her knowledge of the Artist and Painter's hobbies within the group to propose abstract paintings as a way for participants to visually express the contrasting transformation previously described. The Artist and Painter agreed to create a pair of paintings using the visual metaphor of contrasting colours, informed by this conversation (Fig. 50). Whilst the paintings themselves are authored by the artists (they added their signatures to the paintings), this excerpt highlights how the group shared sensemaking in planning these visuals—co-creating the visual metaphor that was then individually expressed through painting.



“In the lower left corner: a prison; ‘what can I do with this disease?’ The bleeding heart: pain; a lake of blood. The yellow bits: yellow people, like the sun; the giving of ideas. Along the bottom: at the start all is dark. At the top (colourful): good things; caring.”



“An explosion of joy and light and life. It’s how I feel inside... not today, I’m getting there, but most days inside.”

Figure 50: Abstract paintings and artist statements made by the Artist (left image) and Painter (right image) respectfully. Photo by Author.

The group’s discussion about using colours as a visual metaphor continued, with the conversation moving to talking about how words could also depict this contrast. I proposed including a ‘love letter’ to the peer support journey within the zine, which reminded the Poet of a poem she had written and shared with the group previously. With permission from the Poet, the Art volunteer began reading a few of these poems aloud:

ART VOLUNTEER: “looking through the looking glass, I see the dreams, I want to be true. Days are hard, I know to be true, but I know this much is true. I know we are strong enough to make our dream come true no matter what is thrown at us, hand in hand we can do this, I know this it’s true; shoulder to shoulder, arm in arm.” well then the other one, another one is “along the way I lost myself. But with the love and support of our women, I saw a light. Each of us has lost out way, doubting ourselves...”

POET: I think that one. (PAINTER: mm)

Art Volunteer: I like this one!

ARTIST: That one

POET: Yeah I don't really like 'the looking glass' one

ARTIST: that one is good.

ART VOLUNTEER: "Doubting ourselves along the way, found it hard to stay, but with the love of our group we helped each other find our way." (pause) and the last one, I like [the earlier poem] for what we've been saying. (presenting the next poem) "a tear that fell today, was not like before—that tear of loss and dismayed, it is a tear of happiness and joy, we have conquered all. We have love, hope, and friendship, and with this it keeps us grounded."

ARTIST: that's good.

PAINTER: yeahhh, that one.

ARTIST: that one.

ART VOLUNTEER: what about you [MAKER]?

MAKER: This one is going to be, at the end [of the book].

ART VOLUNTEER: at the end.

MAKER: yes, as the conclusion.

Through this conversation the group selected the two poems used within the final zine and their placement (Fig. 51). These poems artfully describe the contrasting experiences voiced by the Poet and Painter, moving from feeling "lost" to "tear[s] of happiness". Their placement at the start and end of the zine communicates this contrast further, framing the narrative as a journey from difficulty to happiness with peer support.

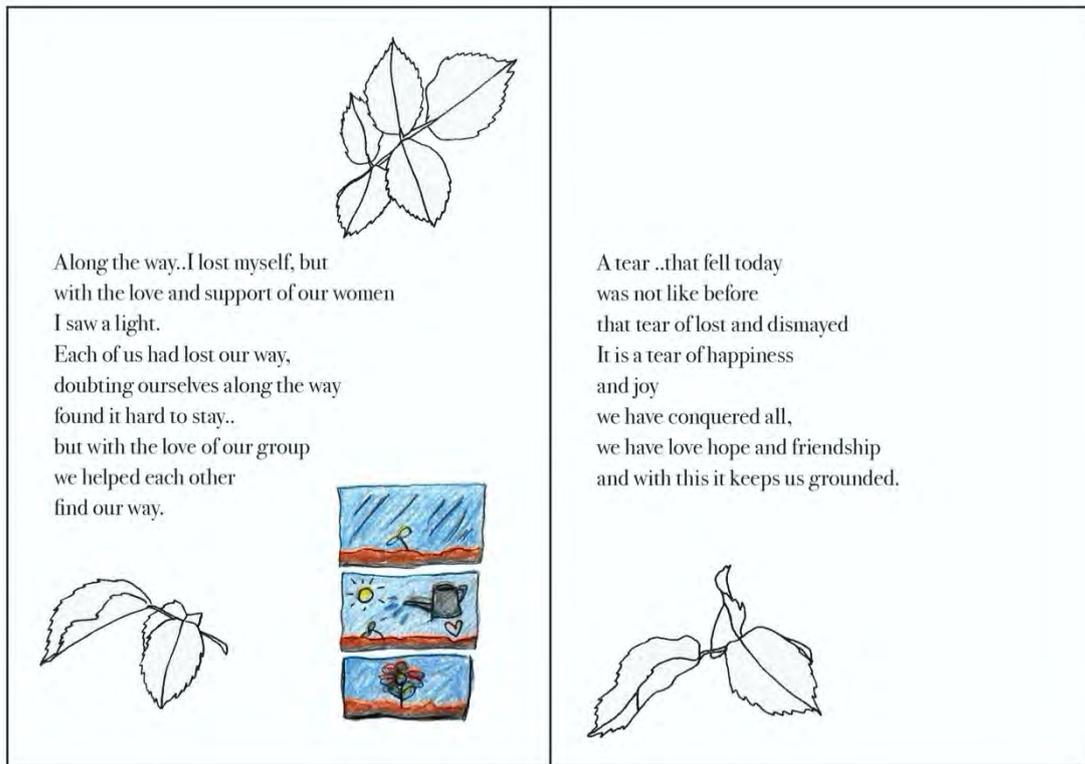


Figure 51: Poems written by the Poet, included at the start (left) and end (right) of the zine respectively. Photo by Author.

During study activities I observed how participants artfully expressed the positive transformation that peer support had facilitated within their lives using abstract and poetic media. These works drew on the Poet, Painter, and Artist's existing talents in poetry and painting, which the Art volunteer had noted during group discussions. While the individual works are reflective of their creator's unique experiences, their abstract visual expression meant that other members of the session could empathise and contribute their own input using the same languages— giving examples of colours or their opinion on poetry. I reflected on how the language of these material artefacts allowed others to relate them to their own experiences, inviting them to connect and contribute to the conversation of change. In this way these artefacts imparted a *relatable* narrative of change, creating points for the viewer to consider how their own

experiences could relate to the ‘moving forward’ narrative that peer support facilitates.

These visual artefacts (and their descriptive statements) communicated how a narrative of ‘moving forward’ could acknowledge severely negative experiences without depicting traumatic experiences literally. Using abstract visual elements, such as poetry or abstract painting, allowed for narrative focus to remain on the good to come from involvement in a peer support journey rather than highlighting the negative experiences that a viewer may be entering from. By acknowledging these negative experiences, the ‘moving forward’ narrative was further enriched; communicating how severe experiences (that may be relatable to a viewer) could be moved through in one’s journey with peer support. The stark contrast of language and colour within the zine artefact also visually expressed a clear narrative structure (beginning/end), strengthening the communication of future-focused ‘growth’ as a key aspect of the journey.

7.5.1.4 “Opening up... starting to lift”: Growth through positive experiences

The participants had created several zine pages that expressed the positive events and experiences that their peer support journeys had included. These pages tended to use more images than words or phrases. When presenting the zine page that she had made (Fig. 52), the Poet described the feeling of opening to these positive changes in her life as an umbrella opening:

“[T]he umbrella is like... do you know when the umbrella is shut, and you feel like, closed in? That’s what we’re feeling [before peer support]. And then when the umbrella opens up, you start to... lift? (ARTIST: [You] open your eyes...) Yeah, yeah.” [Poet]

In her zine page, the words ‘under protection’ appear under an image of an open umbrella—expressing how ‘opening up’ through her peer

support journey has given her a sense of security and protection. The Poet’s reflection on her collage illuminated how involvement in peer support had helped her ‘lift’ from her negative past experiences to her current positive state, which the Artist related to as “open[ing] your eyes”—being receptive to brighter things. In this way the zine artefact prompted co-created shared understanding of how involvement with peer support had helped some participants open themselves up to new, positive experiences.

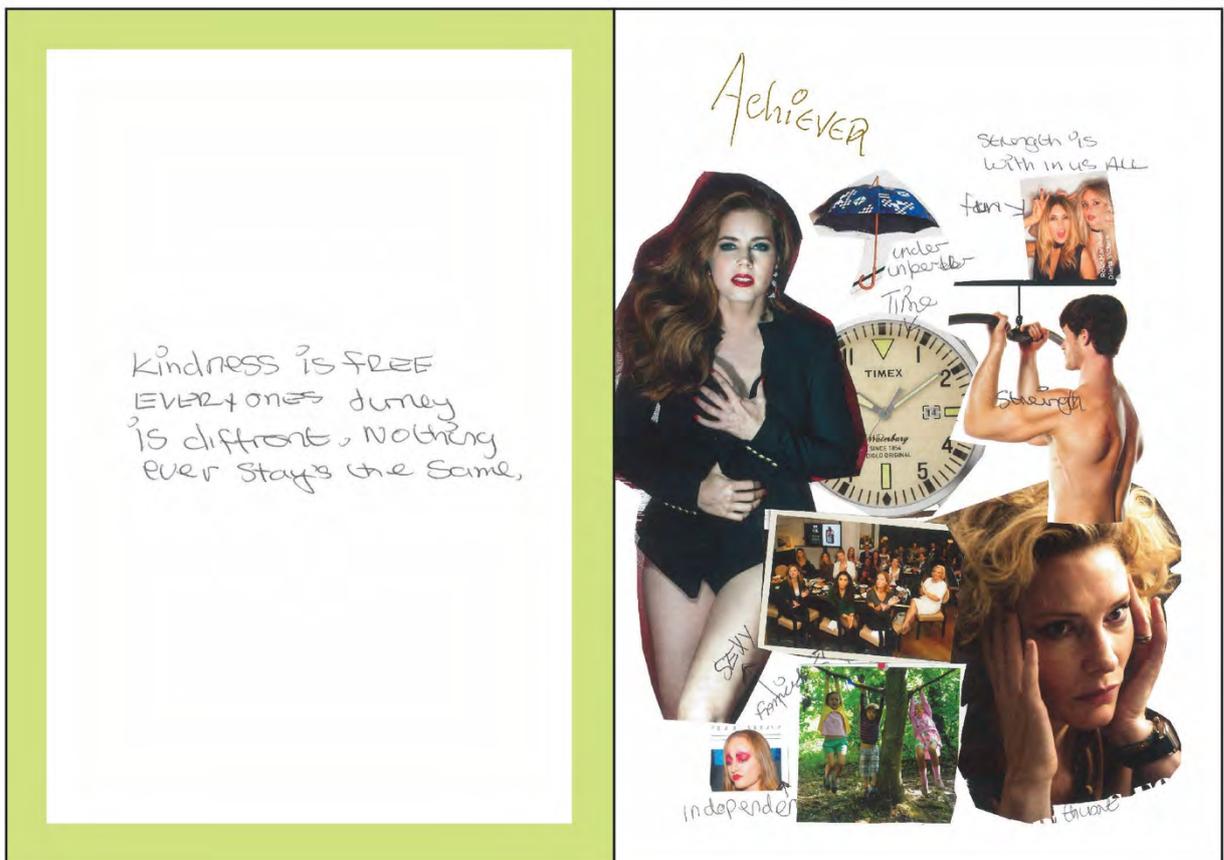


Figure 52: Zine pages made by the Poet. Photo by Author.

The Poet went on to describe how her zine page (Fig. 52) depicted several other positive strengths that she had gained through being involved with the group:

“This one there (image of two women making faces) is just ‘Fun’. Messing about. Yeah? And that one there (man working out) is ‘Strength’, because he’s in a gym. [...] ‘Friends’... my

friends around here [at BST] are very important to me. 'Independence'... (pause) and 'Sexy'. Feeling sexy in yourself. Cause... I didn't feel anything in myself, I just been this (pause) empty shell... and [then] 'I started to feel, like me again? So it's sort of like that? That sort of feeling. [...] Like being reborn—yeah."

Reflecting on her collage, she expressed the various positive elements that she had experienced since being 'open' and 'lifted up' through her journey, such as feeling confident, fun, social, and desirable. These elements were visually explicated with images and words within her collage, communicating the variety of positive attributes that peer support had helped grow in her life.

Joy and pleasure as therapeutic elements of peer support were highlighted as key parts of the group's activities in this collage and several other zine pages. Reflecting on this, I recalled how previous qualitative research with women living with HIV (Sophia Forum & Terrence Higgins Trust, 2018) highlighted that whilst not everything was about HIV, HIV could complicate accessing some forms of care. Weaving positive experiences into the zine's narrative of change communicated how the peer support journey involved aspects of joy and connection as means of providing care.

For example, the zine pages made by the Maker also used imagery and language to express positive sentiments related to her experience of the peer support journey. This included pages on the love, care, and encouragement she had received in the group (Fig. 53, left), and the various group-led experiences (such as nature walks and tasty food shared during meetings) that had brought her joy and happiness (Fig. 53, right).



Figure 53: Zine pages created by the Maker, expressing valued strengths of care and happiness. Photo by Author.

When the group discussed the Maker's pages the Painter highlighted how helping to provide positive experiences for others at BST served as a form of care for both others and herself:

"I think that... ehm... like, like... w-with us, you know, we-we've come quite a long way haven't we? ...A long way. And now... like, me and, and a lot of the others (gesturing to other participants), we help each—other people... We—help with the other groups [at BST]... and that helps you by helping other people... [W]hen [you] say 'caring', giving out[ward], that helps you—not focusing on your own problems, and-and you know, as you say, like... the thing we're doing now [in making the zine], this is for people who [have] just came into it; and you know how you felt when, when it first happened, so therefore you... you know? We're doing this to give something back as well... it's really important." [Painter]

Both the Maker's zine pages (Fig. 53) and the Painter's utterance illuminate how the journey of peer support allows for service users to both receive and provide forms of care; both acts serving as a means for service users to grow. This understanding builds upon the Poet's zine pages (Fig. 52), describing her journey of being 'lifted up' through her relationships with other group members and the fun experiences they have shared. This is visually communicated through the positive images and language used throughout the zine, weaving positivity into the narrative of change caused by involvement with peer support —making the care and fun experienced a part of this journey of growth rather than merely activities within in. Through these pages, participants express the value of positive experiences being shared amongst the group, opening them to others as they move forward together through the journey of peer support. These sentiments, depicted alongside images of joy, love, and peace, express the importance of these positive experiences as both events and states of being facilitated through the journey.

7.5.1.5 Balancing the Plurality of Positive Experiences: A Note on the Miniature Food Zine

Because the images used to express positive experiences were often direct representations (e.g. images of food used to represent food), some of the images used did not represent things valued by all participants. This issue arose when discussing several zine pages that had been made by Mama, all depicting various foods that she enjoyed. When reviewed by the group, the Poet raised that she did not enjoy looking at images of food because her appetite had been suppressed by her medication:

POET: yeah; I don't know about you (to other participants) but I did- I don't have any appetite. Food doesn't do anything for me...It's horrible – I can't eat anything... I just have no appetite; the medication I'm on suppresses your appetite.

[...]

ART VOLUNTEER: did you used to enjoy your food?

POET: I did yes. Yeah.

Because several pages about food had been made, their inclusion in the final zine would take up a large section of the booklet, potentially overtaking the focus of the zine. Considering that the zine was meant to communicate to a diverse audience (which may include others that did not enjoy images of food) I proposed including these pages as a miniature zine, one that could fold out to be read or left alone if the reader was uninterested (see Fig. 54). The participants were excited by this idea and enjoyed the 'fun' actions of untying and stretching out the miniature zine in the final versions.



Figure 54: The miniature food zine, shown closed (left) and open (right) within the final zine. Photos by Author.

Upon reflection, including the food pages as a miniature zine allowed for the plurality of positive examples to co-exist while balancing conflicting opinions. In this way both Mama’s work and the concerns of the group are reflected in the final zine.

7.5.1.6 “All about patience and time”: Clock faces and the importance of temporality

Metaphors about the passage of time appeared throughout the zine study, both in the zine artefact and in the language used by participants when talking about their collages (e.g., “you can only go forwards, you can’t go backwards” [Poet]). This was most explicitly expressed visually by the reoccurring use of clock faces in two separate collages (Fig. 55-56 below) by the Poet and Artist, respectively. In presenting their collages, both participants described the clock as a metaphor, representing the concept of time passing, and expressed the significance of this in their lives.



Figure 55: Collage made by the Poet, featuring an image of a clock face.

Photo by Author.



Figure 56: Collage made by the Artist, featuring the image of a clock face.

Photo by Author.

For the Poet (Fig. 55), the importance of time related to her late diagnosis and initial prognosis of only two weeks:

“And that [pointing to watch face] is time. I have a thing about time. [pause] I collect watches now. I’m obsessed with time. I think it’s because they only gave me two weeks to live, and... it’s just... (ART VOLUNTEER: precious?) Yeah in my head now, about time... Yeah—I have to do (PARTICIPANTS: certain things), yeah on the go, on the wheel all the time now; I can’t stop, (PAINTER: like a hamster) I can’t stop; yeah. If I sit—if I sit down, I lose time... time is very important to me.”
 [Poet]

For her, time was something to be valued and utilised to its maximum potential. As living with HIV had meant an extreme personal reflection on the time available, the Poet expressed time as an obsession; something important that should not be wasted.

While the Artist also highly valued time, she identified and represented time (Fig. 56) by having patience:

“Time for me is so... a big word, ‘time’, time... losing time; smart time; no time, to do the things... more time, to go... to go to that place, with the other[s]; n—no timetables. And... the... quiet-ful-ness that we have, in this place [peer support group]. We need quiet. We need quiet moments. In our busy lives... being patient. Is a gift. Yes it is. And very hard to obtain. To be a patient person. (Pause) You must waaait, a loooooot of time for this, for that, for anything... (pause) to know how patient, how patient [you] will be. Like waiting in a hospital... like waiting for the time [to] pass or, any reason or... That’s it; all about patience and time.” [Artist]

Unlike the Poet’s experience of being “on the wheel”, the Artist found patience with time brought peace and strength to her experience of living with HIV. Patience was described as a difficult skill to master and particularly important in settings one could not control, such as waiting in a hospital. The Artist expressed that “quiet moments,” peaceful moments away from everyday bustle, were a respite of value and importance that the BST peer support group facilitated.

While these expressions of time differ, they both highlight the importance of temporality in the peer support journey. Through conversations about these collages participants discussed how time related to a larger narrative of temporality in their lives; as stated by the Poet, *“Time rules our lives”*. When considering how time ‘ruled’ their lives, the Poet raised the added value of the time spent within the peer support group as a time to heal, building on the Artist’s valued *“quiet moments”*—enjoyment of the present time with the group:

ARTIST: Take advantage, the time that is near us now; this moment. So good.

POET: Our healing time.

Within this utterance, the value of peer support services is remarked upon as something important in the care of these participants: a

space and time to heal and enjoy. The Poet and Artist both describe wanting to have a positive relationship with time—making the most of and treasuring every moment. This foregrounds the importance of peer support services retaining a temporal healing space and time in their lives, highlighting the value of having a time and space to return to and heal with peers.

7.5.2 Process (SRQ2)

7.5.2.1 Production of Zine Pages

In relation to the content of the zine itself, my expertise as a professional designer was often desired more in relation to my practical knowledge of producing publications (making printed materials) rather than creative input as an ‘expert’ communication designer (making visuals). Although participants generally wished for no visual changes to be made to their individual collages, small adjustments were permitted to improve legibility, print quality, and better align the final pages with the author’s intentions. This included slight adjustments to image placement to support visual cohesion between pages; digitally enhancing handwritten text to improve legibility; and moving the handwritten titles of collage pages onto separate pages (Fig. 57). For these design choices, I drew upon my practical expertise in printing, graphic design, and digital editing.



Figure 57: Images showing the original zine page made by a participant (left) and its appearance in the final zine (right). Photos by Author.

My creative involvement was instead related more to supporting the editorial process of making a zine booklet out of individual pages. Providing multiple examples of work-in-progress was well received by participants and supported dialogue about layout preferences and other design decisions. For example, Fig. 58 below depicts three mock-ups of how colour could be added to the collages to link pages together throughout the zine. The participants unanimously chose the border (centre image in Fig. 58), with the Poet explaining “[it] looks nice... makes the page stand out”. I selected initial border colours, pulling them from their associated collages, which were later approved by the participants.



Figure 58: various mock-up images of how colour could be incorporated into zine pages. Photo by Author.

Additional pages were also added to the zine through editorial discussions that I held with the participants and BST volunteers. These pages included the poems that open and close the zine, the pages with handwritten strengths and rose imagery, and the paintings with artist statements. These pages were collaboratively prepared with participants, with some new visual elements (e.g. the rose illustrations) being made my me. The style of these new visuals was guided by requests from participants, with final versions only being included in the zine after being reviewed by participants. Providing multiple examples of page layouts supported this collaborative process well, allowing for final design decisions to be controlled by participants and giving space for new ideas to be included.

Overall, participants preferred to maintain editorial control over the main visual content of the zine (collages), and maintain some control (choice) over the inclusion of supporting visual elements (e.g. colours). Production-related aspects (e.g. rendering image print quality) were left to me.

7.5.2.2 Production of the Zine

The physical production of the final zines was carried out entirely by me due to access restrictions to the necessary specialist equipment (such as paper guillotines) and the time and physical labour needed to produce the zines themselves (Fig. 59). Certain production tools would only be available to me at my Design School workshops, accessible following expert training. Various elements of the zine required a time and labour-intensive process of producing, assembling, and binding elements by hand. These factors made a collaborative production process unfeasible, so dialogue about the material production of the zine was instead supported through regular in-person 'updates' with the peer support group. These took place over the course of three months (November to February) during the group's regular meetings, once the main study activities had been completed.



Figure 59: Photos of the zine production process (clockwise from top left): printing; folding and awl punching; constructing mini zines; saddle stitch binding.

Photos by Author.

Production design choices (such as materials to be used and print finishes) were discussed during these update meetings. Examples of various materials, finishes, and bindings were sourced or produced in response to participant feedback, and participants made final choices from presented options. For example, during a production update, participants requested a thin ribbon bookmark to be added to the zine. I sourced several ribbon options in a variety of colours for the following week, and then participants selected a green satin ribbon to be included in the finished artefact. The meetings helped support an

ongoing connection with participants throughout the production process and supported a feeling of shared ownership of the final zine artefact.

The meetings also served an analytic function for me, as part of the co-creative activity of designing the final zine artefact. In defining material choices together, we co-created a shared material language (or style) for the final zine. For example, The red stitched binding and green bookmark draw from the colours of the bloomed rose and 'strength' labels on the front cover. I felt that the repetition of these visual elements (colours) helped *bind* the plurality of the zine pages together as a cohesive whole: one booklet representing a range of experiences communicated through a common (material) language. As an 'expert' designer, I was able to support the development of this material language by sourcing and offering several material options, keeping production meetings focused on Making sense of what materials would best communicate intended meanings.

7.6 Reflections on Praxis

Although I had initially aspired for the zine to offer an example of a sequential peer support induction process (like the initial onboarding process of an app), the narrative of the zine took a different route. The zine's narrative is an abstract and emotional journey of growth, entwining heavy (e.g., "losing one's way" in life) and light (e.g., enjoyment of food) experiences throughout. While this journey is presented as an unfolding understanding, rather than a series of steps, the zine's central narrative of growth still communicates the process of change effectively. This outcome was completely different from what I expected when I first proposed this study.

Upon reflection, I realised that I had approached this study as an interaction designer, using design methods to illuminate how explicit

insight could be translated into a series of objective design parameters for digital tools and services. I had not considered that the peer support journey might be difficult to communicate as a linear process, despite being captured within a sequential medium (a zine booklet). By crafting the zine together with participants, my beliefs about the peer support journey were challenged and changed—my understanding of the function of peer support services changing through dialogue and reflection on what we had made together. By letting go of my previous understanding, we made a zine that expressed how various aspects of peer support services contribute to the subjective experience of growth and change within the peer support journey. The flexibility of the zine making method allowed for this alternative narrative to be expressed through the plurality of zine page topics and the material language of the final zine. Collaborating on making the design artefact, allowing it to become crafted into something best suited to the emergent narrative, provided the space for this alternative conceptualisation of peer support to emerge. I learned that the peer support journey is an active process of change, subjective to everyone, which static requirements would never be able to fully capture.

This study informed my understanding of how peer support services do more than provide explicit services or skills, additionally creating an *ecosystem for growth* within the peer support journey. The visual metaphor of a flower blooming offers a fitting representation of this: whilst the outcome of personal growth may be akin to a flower growing from a seed (changing from state A to state B), the process of growth itself is created through the entwinement of several interconnected and concurrent factors (e.g., sun, water, and soil), which may need to be configured differently for each kind of plant. Similarly, the journey of peer support is not a path from point A to point B, with services and tools acting like steppingstones, but the

creation of the environment people need to survive and thrive. This environment weaves together various tools, events, and experiences to provide the support for service users to grow forward in their lives.

Co-creating the zine artefact meant individual experiences of this journey and how it involved these various aspects were explicated to others, prompting discussion and connections in response to the language used (both visual and spoken). While exact experiences differed, connections between visual and spoken languages illuminated a 'core of sense' about the journey of peer support that all participants could relate to. In this way co-creating the zine helped define shared understanding of the journey while also creating an artefact that reflects what peer support does—inviting the viewer to consider how their story relates to others whilst reframing this shared narrative towards a positive future.

These reflections helped me address my third PhD research question (RQ3): *What approaches can inform design praxes involving Digital Health tools and services within stigmatised health contexts?* My insights were twofold, highlighting the importance of both (1) *co-designing* artefacts and (2) the co-designed *artefacts* themselves for Interaction Design research in stigmatised health contexts.

Firstly, the insights from this study are completely different from what I had initially imagined. I didn't consider how the zine's narrative could be structured differently; I had never thought of HIV peer support that way because *I had no lived experience of using HIV peer support services*. Using a co-creative method led by the input of women living with HIV allowed for a new narrative to emerge, one that lifted up the lived experience of service users and allowed for my understanding and assumptions to be challenged. For new narratives to emerge design praxes need to provide the space and support for

them to be expressed and allow them to impact emergent artefacts. Whilst facilitating this space and support within design processes is a core focus of PD, PD discourse often focuses on the process of eliciting insight, not how the insight impacts resulting artefacts or interventions. This is important within stigmatised health contexts, as stigma is created by beliefs and therefore likely impacts how a designer interprets the purpose or user experience of a service. If a designer doesn't know the meaning of what they are designing for they can't know the form that that meaning will be best communicated through; resulting in a final output that likely reflects the designer's own, imperfect (and potentially stigmatising) understanding of an experience rather than the needs of a user. In this zine study, understanding how peer support services provide a nurturing ecosystem for growth has been key to understanding the full impact of these services in the lives of women living with HIV: peer support services are about supporting the journey, the *process* of growth, not an end destination. Giving up control of how these narratives are constructed and expressed through co-creative Making activities provides the means for designer-researchers to learn what needs to be said and how it this is materially translated.

Secondly, the co-created zine itself helps support the translation of this new understanding by giving tangible form to beliefs. Understanding the journey of personal growth through the visual metaphor of plant growing from "rough" to "beautiful", rather than say 'levelling up' or 'travelling to a destination', offered additional insight into the experience of the peer support journey. Having this meaning be communicated through an artefact (zine page) meant that others could review this visual translation, expressing how the imagery related to their own experiences. By making the artefact together participants combined and related their own pages with others, co-creating a shared narrative, or 'core of sense,' that they could all

relate to. This emergent zine could then be shared with new referrals to the group, inviting them to engage with the 'core of sense' the group shared (an introductory stage of peer support) and providing a means for existing group members to provide 'care' for others—an important aspect of one's peer support journey voiced by participants. In this way the artefact served triple purpose: communicating the value of peer support to new referrals, illuminating new research insight, and providing space for existing service users to grow through a positive experience of providing care for others. This illuminates how co-creative design praxes may operate on several levels within stigmatised health contexts, providing means to facilitate the creation of new services, novel insight, and meaningful expression of beliefs. Co-created artefacts allow for new beliefs to be communicated to viewers, including researchers and viewers alike, in addition to serving pragmatic purpose.

By reflecting on how the co-creative process of making and what was made both served to express and challenge beliefs, I gained new insight into how co-creative approaches could inform design praxes involving Digital Health tools and services within stigmatised health contexts. These processes and products offered opportunities for beliefs to be challenged in relation to a designer's intangible (e.g., narrative understandings) and tangible (e.g., the form to be made) knowledges—understandings that are likely incorrect when a designer does not have experience of a stigmatised health context themselves. Using co-creative Making as the means to explicate these beliefs supports them to be *meaningfully heard* by designers, as understanding how they beliefs are translated through visual language is key to understanding the appropriate form of emergent artefacts. In this way, the process of making together kept me open and accountable to how the beliefs of my collaborators affected

design choices, resulting in an artefact that communicates the experience of the peer support journey better than anything I could have aspired to create alone.

7.7 Summary

In returning to work with the women's peer support group at BST, I set out to explore how co-creative methods could produce tangible representations of the peer support journey as experienced by women living with HIV. Through this process, we would collaboratively make a zine artefact that could independently communicate the beliefs created and strengthened through the peer support journey; providing an example as to what women living HIV would want expressed about this experience and how they would visually communicate this. The zine project was guided by the insights generated through my previous doctoral studies, which had highlighted the importance of intangible knowledges and contextual awareness within HIV peer support provision, and the value of tangible design activities in making intangible knowledges explicit. By making these knowledges tangible alongside women living with HIV, I sought to co-create visual materials to inform how digital peer support tools or services could be visually designed to communicate the *beliefs* that peer support instilled within service users.

Co-creating a zine artefact meant that the beliefs instilled through peer support had to be visually communicated. These visualisations (and their oral descriptions) prompted reflection and discussion among participants on how these languages (visual and spoken) related to their own experiences; The connections between these languages explicating a shared 'core of sense' of what the peer support journey represented for all participants. This study illuminated how peer support services helped establish a supportive ecosystem for personal growth for one's peer support journey

through an entwined network of factors. These factors included supporting acceptance and resilience within service users; shifting focus on negative experiences from explicit events to change; the value of receiving and providing forms of care (e.g., joy, love); and the importance of the temporal space to heal and grow. These factors were represented using distinct language, visuals, and narrative structures, illuminated as unique parts within the interconnected ecosystem of peer support. The format of the zine publication allowed for the plurality of these experiences to be expressed, woven together through common visual metaphors to create a shared narrative of the peer support journey. This narrative then invites the viewer to consider how their own experiences relate to the authors', softly reframing the narrative (or beliefs) of what living with HIV can be in line with beliefs instilled through peer support.

The co-creative zine design and production processes also provided insight into the level of influence participants that desired from me as a professional designer. These processes highlighted how participants desired input and support relating to my technical expertise more than my creative design abilities as a designer. Producing several examples of potential design options (e.g., page layouts and zine materials) allowed for some creative decisions to be collaborative whilst recognising and respecting participants as the owners of the experiences being expressed. While I produced the final zines independently due to the access and labour required, regular 'check-in' meetings supported ongoing connection and communication between collaborators and provided additional analysis insight through the creative process.

Reflection on these insights also informed my response to RQ3: *What approaches can inform design praxes involving Digital Health tools and services within stigmatised health contexts?* This study

highlights how the co-creative design process and production of a tangible artefact offers a medium for beliefs to be challenged. Following this study, I reflected on the importance of this when designing artefacts for stigmatised health contexts, as the beliefs of a designer likely differ from service users if they are not a service user themselves. If a designer does not understand what is important to communicate or facilitate, they cannot design the form of an artefact to best support that translation of meaning or purpose. This incorrect translation may result in a poorly designed tool or service, or worse, if based on stigmatising beliefs gone unchecked. Reflecting on these concerns after my experiences within this study, I felt excited by the potential co-creation offered for my own design praxis and for other designers working in complex or stigmatised contexts within Fourth Wave HCI (Frauenberger, 2019), where both making and what is made matter.

8 Discussion

I began my doctoral project motivated to make my expertise and time as a doctoral candidate as useful as possible for women living with HIV in the UK, within the limits of my abilities. As a feminist designer-researcher, I was aware of my positioning as a White, Canadian cisgender woman not living with HIV, and of the potential for my design praxis to be misrepresentative, harmful, and extractive. In response, I sought to find a way to engage in my design praxis meaningfully and responsibly whilst working in a complex socio-cultural context and in potentially sensitive settings. By doing so I further connected with interdisciplinary discourses in the Social and Health Sciences, and in Arts and Humanities.

In the previous chapters I have described how my PhD journey progressed as a programme of work. In Chapter 8, I relate the insights from my studies to my original research questions, aims and objectives to consolidate my learnings and proposed contributions. In addition, I offer reflections on the limitations of this work and speculation on potential future studies engaging Fourth Wave (Frauenberger, 2019) HCI Design praxes.

I now return to my original research questions (RQs):

(RQ1) How does lived experience impact on the conceptualisation and use of digital technologies by women living with HIV in the UK?

(RQ2) How are digital tools and services designed and used within HIV social support services for women living with HIV in the UK?

(RQ3) What approaches can inform design praxes involving Digital Health tools and services within stigmatised health contexts?

In responding to these questions, I offer transferable insights for interdisciplinary discourses involving the design of Digital Health interventions for women living with HIV in the UK and designers working in complex or stigmatised health contexts.

8.1 RQ1: How does lived experience impact on the conceptualisation and use of digital technologies by women living with HIV in the UK?

In order to design appropriately using digital media, it was crucial that I first understood how digital technologies were conceptualised and used by women living with HIV in the UK in their daily lives. In Chapter 2, I described how extant research highlights the importance of understanding the contextual use of digital HIV interventions (HIV eHealth). My Contextual Review also highlighted the lack of eHealth work engaging with the experiences of *women* living with HIV in both the HIV (2.1.3.2) and HCI fields (2.1.4).

In the UK, women living with HIV are increasingly reaching older age, and have statistically lower incomes and greater need of social support services than men with HIV, who are primarily men who have sex with men (MSM) in the UK epidemic (Public Health England, 2020b). However, there is very little research into how these socioeconomic factors impact the conceptualisation and use of digital technologies (Lockhart et al., 2021; Marhefka et al., 2020). Furthermore, women are under-represented in HIV research broadly (Curno et al., 2016), and specifically in research about how social context relates to the design and use of digital HIV interventions; the limited available research reveals the diversity of experiences

globally (Blackstock et al., 2015; Hay et al., 2020a; Lockhart et al., 2021; Marhefka et al., 2019; Natarajan & Parikh, 2013).

In response to this gap in knowledge, I conducted two empirical studies, reported on in Chapters 4 and 6, that explored the use of digital technologies for HIV social support service provision by women living with HIV in the UK. Through these studies I address research objectives for RQ1: gaining empirical insight into the factors impacting digital technology use by women living with HIV in the UK. In the following subsections I consolidate these empirical insights into higher level themes and discuss the key factors, relating these findings to previous research in order to propose my novel contributions to knowledge.

8.1.1 Financial Access & Costs of Ongoing Usage

Using digital technologies comes with financial cost and burden, including buying technologies outright (such as a mobile phone) and the costs of ongoing usage (such as paying for a phone or data plan). Participants in both Chapter 4 and 6 expressed how their digital technology use was shaped by these costs. This expands on previous reports of the impact of socioeconomic status on HIV eHealth usage (Kalichman et al., 2005; Marhefka et al., 2020) and the use and willingness to use different digital technologies for HIV-related purposes (Lockhart et al., 2021), offering further nuanced insights into how women living with HIV use technology within economic constraints.

Participants in my studies reported only using Internet-enabled platforms through a Wi-Fi connection (rather than a data plan) and upgrading mobile phones by trading older models with family members. Participants in Chapter 6 noted how the financial costs of supporting ongoing use of Internet-enabled apps on mobile phones

had presented challenges in the past, voicing concerns about data plan payments and the memory required to store digital tools and services on personal devices. Financial access to digital technologies is often considered in relation to initial access (e.g., does the user have access to a mobile phone). However, these insights highlight the importance of considering financial access in relation to both (1) what digital technologies are being used, and (2) the costs of ongoing usage.

Consideration for the financial costs of sustaining eHealth contributes to existing discourse on the impact of social factors on HIV eHealth interventions. Whilst recent quantitative research in the US has found text messaging on mobile phones to be most preferred by women living with HIV (Lockhart et al., 2021), my research provides contextually-rich insight into how these preferences may be informed (in part) by financial access. This builds on previous findings on the effects of socioeconomic status on digital technology use for people living with HIV (Kalichman et al., 2005; Marhefka et al., 2020). Whilst mHealth interventions have been shown to be acceptable for some women living with HIV (Tufts et al., 2015), the qualitative nuance contributed by this work sheds light on how financial access may impact use. If service use will be affected by Internet connectivity due to financial cost, use of Internet-enabled eHealth services may be limited within specific contexts that have Wi-Fi. This may impact 'when' and 'how' services become accessible. For example, it may be stressful to access an online peer group from home for a new referral if they share the household (and potentially the digital technology itself) with others; or a time-limited service may not be available when someone is at work. Similar experiences to these were voiced in this doctoral work (Chapter 6), managed by the design of community-led digital interventions. The financial costs of accessing Internet-enabled eHealth interventions should similarly be

considered in the design of digital interventions for women living with HIV.

It is also important to note that although all my participants had access to a mobile phone for personal use, these devices were often older models. This presents a challenge when designing digital services, as some apps or functionalities may be limited by the operating system (OS) available on a device. Older devices may not be supported for newer OS updates, potentially limiting who is able to access new digital interventions. Using an older OS also presents potential security risks, as recent security updates may not be supported. Designers should consider how limited accessibility to recent hardware and software may impact the design of digital interventions.

Finally, using digital technologies for service delivery shifts some financial costs to the service user. While some HIV social support services offer financial assistance for transport to/from meetings, this does not currently extend to financially supporting access to digital HIV services. Financial limitations may restrict use of digital tools or services if access requires financial cost, which should be considered in the design and development of digital interventions. This insight is especially poignant in light of the rapid service changes in response to the COVID-19 pandemic, during which many services for people living with HIV in the UK became digitally mediated by necessity (Petretti et al., 2021). In the wake of 2020, HIV clinical and social support services may be digital by default, potentially amplifying existing inequalities in access to services among those from marginalised groups such as women (a group more likely to have socioeconomic challenges). This underlines the importance of hybrid models of peer support service provision for women living with HIV in the UK (i.e. offering both or a combination of in-person and digital

options), echoing recommendations from previous research in the US (Blackstock et al., 2015).

8.1.2 Digital Confidence

Women living with HIV in the UK are increasingly reaching older age, with the majority (87%) of this group being aged 35 and older (Public Health England, 2020a). Participants in my studies reported in Chapters 4 and 6 are broadly representative of this population, with all aged between 35-66 years of age. Whilst all participants were observed or reported using digital technologies (such as mobile phones) in their daily lives, some described feeling unconfident in using some digital technologies. This was unsurprising, given the reported correlation between age and digital confidence in other studies involving people living with HIV (Blackstock et al., 2015; Longinetti et al., 2017). Beyond confirming the existence and impact of digital confidence on digital HIV interventions for women living with HIV, these insights also contribute understanding into how digital confidence has been responded to within service provision. As noted in my Contextual Review (2.1.3.2), digital innovations led by HIV service providers have been largely uncaptured in academic discourse.

In Chapter 4, participants using Blue Sky Trust's (BST) services reported enjoying receiving text messages, a digital technology all were familiar and confident with, as part of peer support service provision. Participants noted how text messages extended the "warm tones" of in-person meetings into a new, digital space. While participants were generally not interested in using unfamiliar digital technologies, recommendations from peers of digital tools they had found useful (such as an app that would allow users to check HIV medication interactions) were well received. Furthermore, group interest in a mobile app recommendation made during this study

prompted organisers to suggest that a future meeting be spent learning to use the app together as a group. This interaction shed light on how the trust fostered within peer support communities may help address digital confidence concerns of service users. The comfort, encouragement, and sense of security created through the 'safe space' of a peer support environment appeared to ease the introduction of new technologies for participants with low digital confidence—supporting them to learn and engage with new digital technologies that may support self-management.

4MNetwork (4MNet) study participants in Chapter 6 described the purposeful choice in using a familiar digital platform (WhatsApp) for service provision. This had been a conscious choice by the group, selecting WhatsApp for its familiarity and accessibility amongst members. Some study participants commented on how adopting new digital technologies, such as Zoom¹⁴⁷, had been difficult for some members. Whilst embarrassment in relation to learning a new digital skill was noted as a factor, participants described how group members worked to maintain a positive and supportive atmosphere as they learned how to use the application features at their own pace. Participants also described how 4MNet's choice to use digital technologies for service provision was pragmatic rather than interest-led, informed by the need to stay connected with a nationally dispersed group at minimal cost rather than a preference for using digital technologies. This echoes related research on digital interventions for women living with HIV in the US (Marhefka et al., 2019). The authors similarly describe interest in using digital technologies for HIV peer support services because they allow access to services, rather than interest or preference in using digital technologies *per se*. Whilst this choice was pragmatic among my

¹⁴⁷ This study was conducted prior to the COVID-19 pandemic in 2020, before video conferencing platforms were more widely used.

participants, the values of the group as a supportive community led to choosing a familiar digital platform that would work for everyone (WhatsApp) and approaching using new technologies with patience and kindness, so that no one was excluded. I found that 4MNet's use and adoption of new digital technologies embedded the values and pre-existing nature of service provision, similar to BST practices.

In both studies, digital technologies were chosen, adopted, and used effectively for service provision by reflecting the needs of their users as well as the values of the services being provided. Digital confidence was most often addressed by using familiar technologies, or by using the values of a service community as means to support digital skills training. In both cases, the form of digital technologies was rendered somewhat invisible, as focus was reportedly kept on service provision rather than how it was mediated. Although digital confidence may be a factor impacting the use of digital technologies by women living with HIV in the UK, these insights highlight the role of thoughtful design choices that reflect service provision. Using familiar digital technologies (such as text messaging) may also benefit peer support service providers, extending the impact of positive social engagements into an additional, digital social space for service users. The supportive environment of peer support groups may also make digital skills training more accessible to some service users, utilising the 'safe space' of peer support to help address discomfort in learning new digital tools.

While 'trust' and 'respect' have been consistently noted as key attributes of effective HIV peer support interventions (Beres et al., 2017; Sokol & Fisher, 2016), this doctoral work's findings offer additional insight into how these attributes may be beneficial for addressing digital confidence and literacy concerns for women living with HIV. Digital confidence may be difficult to address in any

capacity, let alone with users who wish to be anonymous in their service use. The trust established within peer support spaces allowed my participants to feel safe, respected, and supported through the vulnerable experience of learning new digital skills. This environment also offered the opportunity for service users to advise service providers on which digital technologies would be preferred, supporting them to utilise accessible digital technologies appropriately.

Existent HIV and HCI discourses do not capture innovation led by non-publishing entities and individuals (which may include HIV social support service providers), despite these interventions being more likely to be more locally appropriate and sustainable (Beres et al., 2017). Insights from my research shed further light on this reality, highlighting the digital innovation being led by women living with HIV and their social support service providers. Whilst I will discuss how digital technologies are designed and used by HIV social support service providers in a later subsection (8.2), my insights into the meaningful use of familiar, commercially available digital technologies in response to user need poses a challenge to the predominant use of bespoke digital interventions within current academic Digital Health discourse.

Critical reflection on these studies highlights how bespoke digital interventions, common in research work within the HIV sector, may be inappropriate for women living with HIV in the UK. Bespoke interventions create their own systems and interfaces, often relying on a user having an existing digital literacy. This may marginalise users who are not aware of recent trends in Interaction Design or who do not feel confident using digital technologies. This discomfort may also distance users from the service being delivered, as focus will be on how the intervention works rather than what it mediates.

Designers should consider how digital interventions support users to adopt and use their digital tools or service easily, and how the values of service provision may be leveraged to support this.

Additionally, the financial sustainability of bespoke interventions beyond research activities must be considered. Bespoke interventions require technical support, which may not be feasible for HIV service providers to resource. In taking a Fourth Wave HCI (Frauenberger, 2019) approach, it is important for designers to consider the ethical implications of designing interventions that are fit for purpose in marginalised contexts. Novel innovations in Interaction Design may make for interesting research artefacts (Zimmerman et al., 2007), but they may also negatively impact how these interventions are adopted and sustainably used by users and service providers.

8.1.3 Privacy & Security: Social Impact of HIV Stigmatisation and the Importance of Connection

Participants in Chapter 4 and 6 raised how concerns about HIV information sharing negatively affected their digital technology use, when describing their experiences of receiving and providing peer support. This included not wanting to connect with peers or peer groups on some social media platforms, and concerns about what information another person would be able to learn from seeing images on a user's screen. These concerns were often related to the impact of negative beliefs about HIV (or HIV-related stigma), some users wishing to keep HIV-related information private to avoid the potentially negative impacts of sharing this information with others (which they may have experienced previously). The ongoing negative effects of HIV stigmatisation was described by participants in a variety of instances, reflecting the enduring reality of HIV-related

stigma today despite medical and social advances (National AIDS Trust & Fast-Track Cities London, 2021).

Engaging with the ways these experiences affected digital technology use by women living with HIV sheds light on how these considerations evolve during some users' journeys living with HIV. Chapter 4 highlights how the journey of HIV peer support for BST service users included several ongoing relational phases (Family, Friends, Fighters) that changed how they engaged with social support services. Participants described starting as a recipient of safety and comfort (as a Family member), to wanting to actively feed back into the community (as a Fighter). This was reflected in the use of digital technologies within the group: members were texted individually to maintain individual privacy (supporting a sense of Family), while some individuals also used text messages or email to provide support to their peers or the service provider (individual efforts as Friend or Fighter). The use of digital technologies was deeply contextual, with informational privacy concerns being relative to where the user was within their HIV journey and what they were using digital technology for in relation to this. This understanding was echoed in Chapter 6 with some participants describing the efforts taken to ensure the privacy of their mentees in contrast to their personal relaxed attitudes towards HIV information sharing. The security and privacy of HIV information was voiced as being subjective, contextual to each woman's personal journey with the condition.

Because HIV-related stigma is a subjective phenomenon (Goffman, 1990), it follows that security and privacy concerns in relation to HIV information sharing are also subjective. HIV discourse involving digital social support interventions for women with HIV has noted security and privacy as key concerns voiced by participants

(Blackstock et al., 2015; Marhefka et al., 2012, 2019). This doctoral work contributes additional nuanced insight into how aspects of these concerns (those informed by HIV-related stigma¹⁴⁸) may evolve over time. This challenges designers to consider how digital HIV social support interventions can be designed to help support changing privacy and security concerns as they relate to HIV information sharing. Participants in both Chapter 4 and 6 adapted their use of digital technologies to suit their individual needs. For example, text messaging allowed users to receive updates privately (like receiving a letter) or to converse with peers and create an ongoing bond. Features of WhatsApp allowed for group conversations (or the app itself) to be deleted or recovered as needed without affecting the chat for other members, allowing users to control what information was stored on a device that might be shared with others. Participants in both studies utilised digital technologies as *flexible* communication mediators, adapting their use to suit their needs and concerns.

This contribution raises some critical insights into how flexibility may be considered through a Fourth Wave (Frauenberger, 2019) HCI lens. Fourth Wave HCI (ibid.) outlines how the material world is actively involved in meaning making (2.2.3); the things we interact with inform our understanding of the world that we live in. We may ask: what do digital interventions communicate to a user, when HIV social support is presented through the same digital channel(s) that mediate other social connections, such as texting or WhatsApp? Arguably, through this lens (ibid.), HIV information is positioned as just another thing to talk about; challenging stigmatising beliefs that HIV is something to be kept hidden. **This is not to downplay the**

¹⁴⁸ In this I mean to describe security and privacy concerns connected to HIV-related stigma, not security and privacy concerns related to digital technologies (e.g. data privacy).

voiced experiences and very real risks of HIV stigmatisation, but rather to highlight that digital HIV interventions for social support should cater to the subjective needs of individual users and allow for those needs to change.

A user newly referred to an HIV peer support group likely has different privacy and security concerns than a member who provides mentorship; they are in different places along their HIV journeys. While privacy and security concerns may ebb and flow throughout this journey, this should be at the discretion of the user, not the system. Understanding stigma as a subjective phenomenon, crafted socially, through a Fourth Wave (Frauenberger, 2019) lens highlights how the design of digital interventions can help or hinder the emancipatory intent of HIV social support services. How might digital interventions evolve and adapt alongside users? Taken further, if HIV-related stigma were to disappear entirely, how would privacy and security concerns affect the design of digital HIV social support interventions?

8.2 RQ2: How are digital tools and services designed and used within HIV social support services for women living with HIV in the UK?

In Chapter 2 I surfaced the need to better understand how digital tools and services are designed and how they are used by HIV social support service providers, and the lack of published research in this area. I responded to RQ2 by: (a) conducting studies on the use of digital tools within HIV social support services (Chapter 4 and 6), illuminating how these service providers use ‘infrastructuring’ (Star & Ruhleder, 1996) practices to design meaningful digital interventions for their respective service contexts (DiSalvo et al., 2012); and (b)

reflecting on my experiences as a designer working for NAT (Chapter 5) to consider the translational role of the designer-researcher within interdisciplinary digital HIV intervention projects (Wizinsky, 2019). In conducting this work, I aimed to understand how digital tools and services are created and used by HIV social support service providers in the UK, in order to support responsible research and innovation involving the design of digital interventions for women living with HIV. In the following subsections I discuss how empirical insights and reflections from this work has enabled me to fulfil key research objectives.

8.2.1 RO1: Research insight into how digital tools and services are developed in the field in order to pragmatically align design research activities

In Chapters 4, 5 and 6 I explored how digital technologies are utilised and designed by HIV service providers. The reported studies revealed how HIV service providers utilised both existing¹⁴⁹ and bespoke¹⁵⁰ digital tools for service provision: with BST and 4MNet using commercially available ICTS (such as text messaging, email, WhatsApp, and Zoom) to enable or support service provision; and with NAT creating a bespoke online tool ('Looped in') to extend the impact of their existing research and advocacy work (allowing users to curate and share custom HIV information sets). In all cases, the design and development of digital tools and services was informed by available resource and voiced user needs within each respective service community; aligning these works with CBPD sensibilities (DiSalvo et al., 2012).

¹⁴⁹ Existing digital tools meaning commercially or publicly available digital tools, such as WhatsApp, that have not been created for the service provider's specific purpose.

¹⁵⁰ Bespoke digital tools meaning digital technologies created specifically for the service provider's purpose(s).

Both BST (Chapter 4) and 4MNet (Chapter 6) charities used commercially available ICTs for service provision. These technologies were pragmatically chosen for their financial accessibility and relative familiarity to both service providers and users, facilitating adoption and sustained use. This insight resonates with the call for asset-based design research approaches led by CBPD research within HCI discourse (Wong-Villacres et al., 2020), building on the resources available to communities to support sustainable innovation. In both instances, digital technologies were chosen primarily for their low cost and accessibility—utilising available funds and knowledge to establish and sustain ongoing service use.

Whilst the technologies themselves were reported to be largely unchanged, they were selected, and their use designed, to allow for inclusive service provision. 4MNet chose to use WhatsApp through group discussion, outlining rules of engagement that would allow all members to feel confident in using the digital tool. Clients using BST's services expressed similar considerations, with text messages being sent to peer group members individually in response to privacy concerns (which may differ for individual clients (8.1.3)). In both studies, participants raised how ICTs were utilised in specific ways to *inclusively* suit the needs of *all* users, as voiced *by* users, shedding light on how those providing HIV peer support services for women living with HIV design digitally mediated services.

This approach connects with CBPD's 'infrastructuring' (Star & Ruhleder, 1996) approach to the design of digital tools and systems, which considers how human ways of 'doing' are enabled and supported by digital technologies (DiSalvo et al., 2012). Although the decision to use existing technologies was primarily guided by pragmatic concerns, the choice of digital platform and the ways in

which they were used was *designed* to support the human ways of 'doing' respective to each service. Individually text messaging clients allowed BST to maintain individual privacy within a digital space; whereas email afforded an additional communication stream should clients wish to get further involved with the charity. For 4MNet, the communally drafted rules allowed for group members to feel confident in using the digital tool; and the adaptable functionality of WhatsApp meant users could customise the app to suit their needs¹⁵¹. Additionally, the values of 4MNet as a community meant that managing team members could provide individualised support using the same app, should a group member need to withdraw from group activities for a period. Although neither BST or 4MNet created the digital tools they used, they designed their use of them specifically to suit the needs of inclusive service provision.

Additionally, these design decisions were led by input from service users, echoing the democratic political ideals of PD 'thinging' (Björgvinsson et al., 2012a) approaches to co-designing digital interventions. Furthermore, when taken in consideration with the financial aspects of these design choices, these works evidence how HCI CBPD practitioner Christina N. Harrison defines 'accessible technologies' to be those that consider "all facets of what it means to obtain, own, operate, and maintain technology" (Harrington, 2020, p. 27). These digital tools were designed to be appropriate, accessible, and *flexible* to changing user need; inclusively designing services using existing digital tools to suit the evolving ways of 'doing' service provision that women living with HIV in the UK need within social support. These worked examples contribute evidence of how CBPD

¹⁵¹ E.g., customising how notifications were displayed on a personal mobile phone; deleting/restoring group conversations as needed without disrupting the group for others.

'infrastructuring' approaches may shape the material form of accessible and sustainable Digital Health technologies.

Two opportunities for design research activities arise in reflecting on how designer-researchers might pragmatically align their work within CBPD digital intervention projects using existing digital technologies. Firstly, expertise in a variety of digital technologies allows HCI designer-researchers to contribute novel insights into how service providers might utilise additional features or functionalities suited to their service provision needs. This may be especially useful in areas where expert knowledge of digital systems may be under resourced, such as reviews of ICTs for specific service applications (such as text messaging) or facilitating digital skills training. To support this approach, designer-researchers should be positioned to support service providers as a critical friend (Warwick & Young, 2016), providing professional expertise to help inform the choice of digital tools and support sustainable service development as a collaborator working in coalition towards community-led goals. Secondly, as noted in my Contextual Review (2.1.3.2), there is *extremely* limited published research on how HIV service providers use digital technologies for social support service provision. Academic research may explicate rich insight into how digital HIV services have been shaped in response to user need and service provision aims, revealing accessibility considerations (Harrington, 2020), usability factors, and key components of service provision valued by users. Beyond the wealth of untapped knowledge this offers, published research may also support service providers by providing empirical evidence with which to influence policy or support funding bids—shedding light on the innovative work being done and the value of social support service provision.

Insights gleaned from my work with the NAT contribute additional knowledge on how designer-researchers may pragmatically apply research activities within development projects involving *bespoke* digital tools.

Reflection on my work with NAT on 'Looped in' (Chapter 5) provided a worked example of how bespoke digital interventions are designed in the field. In my reflective account, I noted how the division of responsibilities between NAT and the partnering digital agency required translating NAT's contextual knowledge into defined guidance on what the digital agency should create. This insight underlined the value of designer-researchers as translational agents (Wizinsky, 2019) within collaborative digital projects, a positioning that has been utilised by communication designers working within the context of HIV previously (A. Bennett et al., 2006; Wizinsky, 2019). As explicated in (2.2.3), there is currently limited HCI CBPD discourse on how 'expert' design praxes operate within the co-creation of design artefacts. Reflective insights from my work with NAT contribute evidence of the value of practice-based research activities, such as Making (Chung, 2019), for CBPD approaches to designing bespoke Digital Health interventions. Whilst HCI discourse on how research findings may be better translated to influence the design of health interventions more broadly has begun to emerge (Kirchner et al., 2021), to my knowledge there are no HCI papers that focus explicitly on how a designer-researcher's expert design praxes may productively serve a translational function within collaborative Digital Health research projects that engage sensitive contexts, or the importance of this within stigmatised health contexts. This contribution explicates the value of having 'expert' designers as collaborators within interdisciplinary health co-design projects (Donetto et al., 2014), highlighting how this expertise translates insight into defined forms that may be utilised in service provision.

Using Making activities (Chung, 2019) helped support collaborators to define what had to be made by creating tangible representations of abstract knowledges. These representations could then be refined in response to collaborator feedback, using a rhetorical model of Design (Forlizzi & Lebbon, 2002) common to Communication Design practice, with final iterations being used to define what had to be made. In this translational role, designer-researchers should draw on their expert design praxes, using Making activities to connect knowledge to designed forms and refine this translation with collaborators. Designer-researchers are uniquely suited for this role, given their entwined expertise in design craft (as a means of defining forms) and research (as a means of defining knowledge). This positioning allows designer-researchers to align design research activities to support translational understanding between collaborators while illuminating empirical insights that may be transferable to similar contexts.

8.2.2 RO2: Provide empirical insight into how digital tools and services are used in the field by women living with HIV to inform design innovation

Chapters 4 and 6 provided empirical evidence on how digital tools and services are used by women living with HIV for peer support services. As explicated within my Contextual Review (2.1.4), there is a gap in current HCI discourse on how the social contexts that digital HIV social support interventions are used in affects their use by women. Insights from my studies shed light on how women living with HIV use digital peer support interventions in specific ways, informed by their needs and use contexts. Reflection on how these digital technologies are used through an ‘infrastructuring’ (Star & Ruhleder, 1996) lens underscores how HIV peer support providers have innovatively designed their use of digital technologies in

response to these contextual needs. In this subsection I contribute empirical insight on these innovations and their use by women living with HIV in the UK to inform design innovation for digital HIV peer support services.

Mobile phones were by far the most common digital technology used by all participants for HIV-related purposes. Whilst this echoes previous HIV research (Lockhart et al., 2021), qualitative insight from my work highlight on how this use is coloured by contextual factors. Experiences voiced in Chapter 6 presented how Internet-mediated mobile applications, such as WhatsApp, were predominantly used at home over a Wi-Fi connection; use at home being affected by contextual factors such as the financial costs of Internet access, sharing devices with other household members (such as children), and balancing various work responsibilities. These insights underscore how the *locations* that digital social support interventions are accessed and used in may be constrained for women living with HIV in the UK due to socio- economic and cultural factors. This finding contributes new insight to HCI discourse on how gender-based social factors may affect the success of digital HIV interventions (Natarajan & Parikh, 2013), underlining the socioeconomic and sociocultural factors affecting women living with HIV in the UK. Previous HIV research has noted that White MSM are often used as the standard user for designing digital HIV interventions (Lockhart et al., 2021); my research underscores the importance of considering the intersectional impact of gender on digital technology use.

In response to these socioeconomic and sociocultural considerations, digital peer support interventions for women living with HIV in the UK were designed to be *inclusive* and *flexible* to individual user need. As noted previously (8.1.3), BST chose to only

use individual text messages with peer support group members to maintain anonymity, while clients could also choose to join an email mailing list should they wish to become more involved in other activities. In this way, BST’s social support services were able to be inclusive of different user concerns—keeping peer support services secure and accessible for those wishing to remain anonymous while allowing clients to join additional digital services (should they wish to) as they grew through their HIV journeys. 4MNet’s use of WhatsApp afforded similar flexibility—group engagement rules were initially established to support everyone to use WhatsApp, with members reporting the benefits of being able to choose when they accessed the group, what content was kept on their device, and how the app notified them of updates. Additionally, 4MNet members could leave or return to the group at their discretion; management team members would support members individually in these cases until they chose to re-join the group. In these ways both BST and 4MNet designed their use of digital social support interventions to be inclusive and flexible: allowing all to join and customise services as their needs or constraints changed over time. These designs use an ‘infrastructuring’ sensibility to consider how digital technology may enable and support peer support ‘doing’: providing a safe, inclusive space for all that may adapt to support individual need and interest.

These studies also contribute empirical insight into how digital technologies are used to *extend the reach and impact* of peer support services. BST clients reported how the “warm tones” of text message updates sent by the group’s coordinator recreated the comforting atmosphere of in-person service provision in a new, digital space (4.5.2.3). These interactions allowed the impact of peer support to reach beyond the walls of in-person services, enacting them within a client’s daily life. This enhanced the therapeutic impact of using peer support services (Positively UK, 2017), providing a new

medium for these services to combat social isolation. The value of the extended service reach provided by digital technologies was also noted by 4MNet participants. Women who were geographically isolated from peers, or those whose scheduling would not allow them to attend in-person meetings, spoke of how digital tools allowed them to feel connected to peers who they otherwise would not be able to interact with (6.4.1.2.2). Whilst previous research has noted that women living with HIV value digital technologies as mediators of peer support services (Marhefka et al., 2019), these insights contribute empirical evidence into how using digital technologies may extend the reach and impact of peer support services for women living with HIV; this is evidenced both in terms of the accessibility of services and in the extension of their therapeutic benefits. These benefits are notably not specific to limitations caused by geographic location, illuminating how using digital technologies to enact or extend peer support service provision may be beneficial for a broad range of women living with HIV.

Finally, voiced experiences of how digital technologies are used to provide peer support to others sheds light on how women living with HIV utilise existing digital technologies *to provide peer support*. Peer support has been noted help optimise self-management by allowing people to contribute to the communities that they draw upon for support (British HIV Association, 2018). For 4MNet, an organisation led by women living with HIV, using digital technologies allowed them to continue their peer support work with low operational costs and a dispersed volunteer community—using an asset-based approach to utilise available resources to provide much needed services. Some 4MNet members described additionally using WhatsApp for their own mentorship activities (6.4.2.3.1), drawing on their knowledge of the platform to inform their approach. Similarly, some BST clients reported using using text messaging beyond the confines of the peer

support group, such as when two women were both admitted to hospital at the same time and used mobile phones to provide support to each other (4.5.3.3). These empirical insights contribute new understanding into how the use of digital technologies for peer support provision goes beyond mediating formal services to support the *intent* of the services themselves: supporting service users to develop towards supporting others. People learn how to support others by being supported themselves, *so by being supported through digital channels users may learn how to provide support through digital channels*. In this way digital technologies may introduce a new, digital medium for women living with HIV to contribute to the peer communities that they draw upon for support¹⁵². These works contribute empirical evidence towards how this use is already taking place within HIV peer support provided by women living with HIV in the UK.

Current best practice guidance for HIV peer support provision only mentions digital technologies as an option to access peer support services (Positively UK, 2017). These collective empirical insights underline the importance of understanding how the material form of digital technologies may be utilised to (1) create *inclusive* and *flexible* digital peer support services that (2) may *extend the reach and impact* of existing, in-person services and (3) serve as examples of how digital technologies may be utilised for service users to *provide peer support digitally* themselves. Best practice guidelines for HIV peer support should be expanded to include guidance on establishing digital services and using digital technologies in addition to in-person services. These kinds of digitally mediated and hybrid

¹⁵² This can already be seen in activist work led by women living with HIV in the UK, such as Mel Rattue's #PositiveAffirmationDay initiative (Cricketlv, 2017), which using the digital medium and visual language of social media to promote visibility of the diversity of people living with HIV and challenge HIV-related stigma.

HIV peer support services are already being used in the field and should be captured within academic research to provide transferable insights for other stigmatised health contexts.

8.3 RQ3: What approaches can inform design praxes involving Digital Health tools and services within stigmatised health contexts?

I previously raised (2.2.2) how current CBPD discourse within the HCI field has spotlighted how HCI Design research narratives may bolster stigmatising beliefs or otherwise stereotype marginalised communities (Wong-Villacres, Gautam, et al., 2020), including within Design-led Digital Health research (Harrington, 2020). CBPD designer-researchers have responded to this issue by utilising asset-based (Wong-Villacres, DiSalvo, et al., 2020) and strength-focused (Harrington, 2020) co-design approaches, resonant with a wider movement towards a Fourth Wave (Frauenberger, 2019) HCI paradigm. Within this movement (ibid.), designer-researchers are called to embrace considerations for how socio-material interactions shape the world around us, illuminating the responsibility of Design in affecting these interactions. Arguably, this responsibility has long been the focus of HCI CBPD practitioners, as the socio-material considerations of both CBPD's conceptual approach of 'infrastructuring' (Star & Ruhleder, 1996) and PD's 'thinging' (Björgvinsson et al., 2012) focus on the entwined relationships between designed artefacts and people. However, despite this established methodological understanding, CBPD discourse lacks published insight explicating how stigmatising beliefs might inform the material form of emergent digital artefacts when designer-researchers hold different beliefs from their collaborators. How might 'expert' designer-researchers seek to contribute their craft towards

emancipatory change within stigmatised health contexts when their own beliefs may unintendedly colour their material translations?

In response to this gap, I contribute Community-Based Co-Design Praxis (CBCDP) as a novel extension for CBPD methodology, offering guidance for 'expert' designers (Manzini, 2015) using CBPD approaches within stigmatised health contexts. In the following subsections I contribute additional methodological insights on best practices for designer-researchers engaging in design praxis within complex or stigmatised health contexts using the four pillars of CBCDP: Coalition, Conversation, Co-creation, and Critical Ethics. I additionally contribute worked examples of these best practices from within my doctoral work to inform appropriate design praxes within related research fields.

8.3.1 Coalition

To work in coalition means to work towards a shared goal together as separate individuals, unified through combined efforts. For designer-researchers, this means accepting that we are not experts in lived experience but in *translation* (Wizinsky, 2019), using empathic methods as a means of remaining flexible and accountable for change in our own understanding. As a designer is never 'one with' their collaborators (3.2.1.1), we are accountable for checking our understanding and its material translation(s). In doing so we may take responsibility for how our work represents the experience of others, and the impact of this for our collaborators.

In my doctoral work these 'translational checks' took form in various sense-checking and review processes for research insights, and iterative and flexible design processes within the design of artefacts. Worked examples of this are presented in all reported empirical activities (Chapters 4, 6, 7) and referenced within the reflective

account of my work with NAT (Chapter 5). These processes were discussed and agreed upon with collaborators prior to the start of research activities and remained flexible to emergent need or interest within the research process, in line with CBPR (Coughlin et al., 2017) and community-led (Costanza-Chock, 2020) design approaches. These ‘translational checks’ were also designed so as not to place undue burden on participants and be a meaningful use of their time, in line with recommendations by peer researchers within HIV discourse (Namiba et al., 2016). These analytic research practices build upon Bennett and Rosner’s (2019) first commitment for HCI designers using empathetic methods¹⁵³, methodologically positioning commitment to coalition as a key component of the analytic process. In doing so, coalition partnerships may be codified within the research process, guarding against translation checks becoming extractive ‘check box’ exercises rather than true partnerships in meaning making (ibid.).

To help support meaningful engagements I also provided or created resources to help support a shared understanding of analytic or design activities. This included: making an informational flyer and presenting planned research activities during a weekly peer support group meeting prior to study commencement (Chapter 4); creating regular internal reports, presentations, and designing sense-checking workshop materials (scenario comics) as discussion prompts (Chapter 5); preparing documentation that provided an overview of IPA analysis and summative reports of research findings to support analytic discussions (Chapter 6); planning knowledge-share activities on design craft skills (zine-making, bookbinding) to take place prior to design activities and providing artefacts (zines) as material examples for design inspiration (Chapter 7). These materials were reflective of

¹⁵³ “Rather than to seek to represent another’s experience, we seek partnerships in imagining the design encounter” (C. L. Bennett & Rosner, 2019, p. 9).

the individual research contexts they were involved in and selected to support a common understanding of analytic and design activities amongst collaborators.

The Coalition pillar of CBCDP contributes methodological insight on best practices for engaging in design-research praxes within complex and stigmatised health contexts, calling on designer-researchers to (1) *reposition analytic activities as a collaborative translational process* and (2) *supply the appropriate means to support collaborators to meaningfully engage in analytic activities*. These best practices methodologically support ‘expert’ designers and/or researchers to hold themselves accountable to working in true partnership with collaborators, even if it challenges our own understandings or design sensibilities.

8.3.2 Conversation

To hold a conversation is to see shared understanding as unfolding and built through the responses of others, which may include multiple unique voices. This pillar builds upon two of Bennett and Rosner’s (2019) commitments for designers¹⁵⁴, viewing the use of empathetic methods by HCI designers as an ongoing process of attunement (rather than achieving eternal understanding) that recognises asymmetry (rather than attempt symmetry).

Within design-research praxes, this unfolding co-creation of a dynamic ‘core of sense’ (Stein, 2000) between collaborators is at the heart of Making activities (Chung, 2019) – translating abstract knowledges into objective forms that all collaborators may then reflect upon and respond to. Designer-researchers should consider

¹⁵⁴ “Rather than achieve understanding we seek a process of ongoing attunement” and “rather than attempt symmetry, we recognize (sic) and work with asymmetry” (C. L. Bennett & Rosner, 2019, p. 10).

how their conceptualisation of voiced experiences are like sketches; such conceptualisations should be given tangible form and shown to whomever has voiced the experience, to see if they are appropriate representations or if something has been missed or misunderstood in translation. Creating tangible versions of understanding (such as written work, sketched ideas, or prototypes) supports better attunement between collaborators while also creating new forms of empirical data, which may themselves present or elicit new insight.

Holding myself accountable to being open to new voices or considerations within my doctoral work was supported by Making 'synthesising objectifications' (Stanford Encyclopedia of Philosophy, 2020), or sketched ideas or prototypes representative of my understanding that could be reviewed by others to elicit a plurality of responses. My doctoral work contributes several worked examples of this approach, including reports of initial findings for my collaborators to review and discuss within an analytic process (Chapter 4, 6); using scenario comics and illustration prototypes to discuss and refine the translation of contextual knowledge to the defined form of digital artefacts (Chapter 5); and the zine-making process as a means to elicit a plurality of experiences and define common narratives together (Chapter 7). In each of these cases, Making supported an unfolding approach to design-research that could remain open to the influence of new insight while building towards a 'core of sense' that could inform defined insights and/or artefacts. In this way Making activities supported the definition of research outputs without reducing the plurality of experiences it represented.

The Conversation pillar of CBCDP contributes methodological insight on best practices for engaging in design-research praxes within complex and stigmatised health contexts, calling on designer-researchers to: (1) *produce tangible representations (written work,*

sketches, prototypes, etc.) of their understanding at various points in the research process for collaborative review, feedback and attunement; and (2) utilise these Making activities to *remain open and flexible to changes in their understanding*, so that the unfolding ‘core of sense’ used to define insights and artefacts may reflect a plurality of experience.

8.3.3 Co-creation

Within a co-design praxis, collaborators work as equal partners-in-the-world; together we decide what is made (outputs) and how it is made (process) in order to create our preferred futures. This pillar builds on empathetic HCI design praxes (Heiss, 2019; Wallace et al., 2013) to pursue an ‘expert’ co-design practice that works collaboratively with others to shape the socio-materiality of design processes and outputs—how they communicate beliefs through designed form. Whilst previous CBPD HCI discourse has shed light on how approaching design research involving marginalised communities from the standpoint of community need or damage can reinforce stigmatising beliefs (Harrington, 2020; Wong-Villacres, Gautam, et al., 2020), insights from my doctoral works present how stigmatising beliefs may be communicated through the socio-materiality of designed digital HIV interventions if designer-researchers are not accountable for their material translations.

Crafting designed forms within ‘expert’ design praxes (Chung, 2019) involves a process of translating understanding to material form, which Heiss refers to as ‘material empathy’ (Heiss, 2019). As discussed in (2.2.2), CBPD approaches are unique within HCI Design discourse for their consideration of how materiality (such as available resources) and social context (such as the human ways of ‘doing’) are entwined, arguably positioning CBPD as an ideal approach for Fourth Wave (Frauenberger, 2019) HCI Design

research. However, CBPD and PD discourses have not focused on what their emergent artefacts communicate to the world through their socio-materiality, instead focusing more on how the design processes (defining insights), not craft (applying insights to material form), informs these outputs (Björgvinsson & Sandin, 2014).

Understanding socio-materiality is crucial when seeking to change stigmatising beliefs, as stigma is created and morphed by our experience of being in the world *which is impacted by the material world of artefacts and what they communicate*. In seeking to co-design within a stigmatised health context, I sought to understand how my ‘material empathy’ could be guided by my collaborators. This aim informed my design praxis and, in the process, revealed the importance of socio-materiality for digital HIV peer support interventions.

Participants within my doctoral studies (Chapters 4-7) repeatedly expressed how their needs and concerns for HIV peer support services (including those mediated digitally) evolved through their journeys living with HIV. To me, these most notably appeared to change within an individual’s privacy concerns about sharing HIV-related information—a new referral being very private and a trained peer supporter being more relaxed. This change is empirically evidenced in the voiced changes between the needs of Family and Fighter within the peer support journey (4.5), highlighting how peer support helps service users grow from being comforted to comforting others and adopting different digital channels to support this over time. This change is similarly evidenced within digitally mediated HIV peer support services, such as how 4MNet peer mentors voiced less concern about sharing HIV information themselves but took careful steps to consider how WhatsApp could communicate information that may negatively impact their mentees (6.4.2.3.1). In both cases, digital tools and services and their uses changed over time, their

materiality also changing to reflect the evolving privacy needs and concerns of their users. In this way, service providers considered how socio-material privacy considerations could change over time and selected flexible and inclusive (8.2.2) digital tools and platforms that afforded this growth to their clients.

The growth from service user to provider facilitated by HIV peer support services is a key contributor towards optimising self-management (British HIV Association, 2018). These empirical insights illuminate how service providers *had crafted their use of digital technologies to utilise their flexible socio-materiality for this key benefit of peer support services*—allowing their clients to change how they used digital technologies to support their growth towards adopting a new role, in their own time. Digital HIV peer support interventions **MUST** support users in this growth, or they may stunt it. As previously noted (2.1.3.2), there is little research on digital HIV interventions created and used by HIV service providers and a growing field of HIV eHealth discourse using bespoke digital interventions. These digital artefacts are not co-created, and so their form may only be informed by researchers. My understanding of this phenomena only exists because I sought to understand my collaborators ‘material empathy’: I looked at how digital technologies are already being used by service providers. Without being open to this material understanding through a co-creative approach, allowing it to impact my own ‘material empathy’, I would have mistranslated voiced privacy concerns to mean that all digital interventions should always be immensely private and secure—as the digital agency initially did within my experience working with NAT. It is only through co-creating artefacts with collaborators that these understanding were challenged and changed; otherwise our artefacts would have communicated our own flawed understandings and thereby limited the purposes of the very services they were intended to support.

In order to challenge stigmatising beliefs we need to create artefacts that allow for them to be challenged. HIV-related stigma continues to negatively affect people living with HIV in the UK (National AIDS Trust & Fast-Track Cities London, 2021), however if Digital Health interventions only communicate one narrative, that HIV information is something to be kept secret and hidden, then we are creating artefacts that only reinforce HIV-related stigma. This insight builds on the work of critically-engaged designer-researchers working in stigmatised health contexts, surfaced earlier within my Contextual Review (2.3.8.1), who have highlighted the importance of challenging normative beliefs through the socio-materiality of designed artefacts (DePoy & Gilson, 2014). Co-creation is key to supporting designer-researchers to see beyond their own beliefs and empathetically challenge their 'material empathy'. Design praxes involving Digital Health tools and services within stigmatised health contexts should utilise design-research practices that allow for their translations of research insight *and* materiality to remain open and accountable to their collaborators. This can be supported through using co-design approaches that position collaborators as equal partners, reflecting this partnership through shared ownership and authorship of research outcomes.

The Co-creation pillar of CBCDP contributes methodological insight on best practices for engaging in design-research praxes within complex and stigmatised health contexts, calling on designer-researchers to: (1) use co-design approaches to *empathetically challenge their understanding of both research insights and their material translations*; (2) reflect this partnership through *shared ownership of research outcomes*, including artefacts and academic publications.

8.3.4 Critical Ethics

I aligned my doctoral work to CBPD discourse within HCI through consideration of meaningful utility: making processes and/or things with meaning and value for all collaborators. In establishing Critical Ethics as a methodological pillar, the designer-researcher is prompted to consider how design processes and outputs will *challenge* and seek to *change* the inequalities and negative beliefs they are faced with. This consideration methodologically roots the ethical responsibility of Interaction Design practice (Löwgren & Stolterman, 2007) and the asset and strength-based approaches of CBPD HCI discourse (Harrington, 2020; Wong-Villacres, Gautam, et al., 2020); calling on designer-researchers to utilise research processes as means to enact the processes and artefacts our collaborative partnerships wish to see in the world. By affecting the world(s) around us we can build together towards possible futures.

This methodological pillar is key for design praxes involving Digital Health tools and services within stigmatised health contexts. We all play a role in how stigmatising beliefs are supported or challenged as people in the world, and design research allows us to explicate how these beliefs may take form within design processes and artefacts. Within my doctoral work Critical Ethics informed two key practices: (1) using a CBPR/CBPD approach to guide my research, and (2) co-creating things that mattered.

Firstly, using CBPR and CBPD approaches within my doctoral work allowed me to conduct design-research activities while taking responsibility for how my own work might itself cause harm. By working together with collaborators, I could better understand how research processes and outcomes could be best positioned to serve community needs and avoid potential harm. Worked examples of this can be seen throughout my doctoral works (Chapter 4-7), in which

study processes, materials, activities, analyses, and outcomes were all guided by discussions between my collaborators and me. These discussions helped clarify what would be most useful, such as when BST advised a zine for service delivery over an exhibition (7.1.1); when use of language was flawed, such as within the analytic process with 4MNet stakeholders (6.5); and when I was being overly cautious, such as when I designed a study information flyer for my initial work with BST (4.6). Working alongside my collaborators, Critical Ethics allowed for these insights to be heard and applied to my research process and emergent outputs, attuning my understanding of how my work could hold meaningful utility. Working within a stigmatised health context as a woman not living with HIV meant my understanding was coloured by my own experiences. Working with women living with HIV and HIV service providers allowed me to hold my work accountable for my own misunderstandings and mistranslations within an unfamiliar context while co-creating the useful and meaningful processes and artefacts.

Secondly, Critical Ethics informed my approach to using my doctoral work as an opportunity to create research outputs that served meaningful purpose for my collaborators. As described earlier (2.1.3) HIV social support service providers are under immense strain to provide invaluable services for women living with HIV in the UK—there is more need than can be met with available resources. In this context, I made a conscious choice to use my research activities as a way to create things of value: whether that be research papers (Hay et al., 2020) that could show the value of existing peer support services for potential funders, or artefacts that could be used for sustainable service provision (Chapters 5, 7). When faced with inequality, designer-researchers have the opportunity to use research activities as a way to work alongside communities to respond these issues. Co-creating research outputs that may serve

purpose, whether that be as evidence of success or as sustainable additions to service provision, is an opportunity to help make possible, positive futures a reality.

The Critical Ethics pillar of CBCDP contributes methodological insight on best practices for engaging in design-research praxes within complex and stigmatised health contexts, calling on designer-researchers to: (1) *utilise community-based approaches to attune your understanding* of how design-research processes and artefacts may avoid harm and offer value to marginalised communities; and (2) *co-create research outcomes that serve meaningful purpose* for all collaborators in order to use the opportunity of research to build towards preferred futures.

8.4 Contributions

In this section I provide a summary of the proposed novel contributions of this doctoral work to research communities in the HIV sector and the HCI field, organised in relation to their respective RQ.

8.4.1 Contributions involving RQ1: How does lived experience impact on the conceptualisation and use of digital technologies by women living with HIV in the UK?

In responding to RQ1 I contribute novel insights for research communities in the HIV sector and the HCI field into how financial (8.1.1), digital confidence (8.1.2), and privacy and security (8.1.3) factors impact digital technology use by women living with HIV in the UK, based on their reported experiences.

Financial access, digital confidence, and privacy and security are long standing usability factors for researchers working in HCI and related fields, including HIV (Warner et al., 2019). However findings presented in my PhD thesis reveal how these concerns are

intersectional and subjectively nuanced for participants. Women living with HIV in the UK have lower income and higher need for social support services than men (Public Health England, 2020b), making them more vulnerable to the negative impacts of ongoing austerity measures. They are also demographically diverse (Public Health England, 2020a), with a range of ethnicities, ages, and lived experience that intersect with social disadvantage to shape individual service user experience and need (Sophia Forum & Terrence Higgins Trust, 2018). In response to this complexity and lack of resources, HIV service providers have innovatively adopted and adapted existing digital tools and services; using familiar or free digital tools to facilitate access, adoption, user-led adaptation, and continued use. This approach considers digital technologies as a medium for service provision, leveraging the existing and considerable strengths of peer support services to facilitate digital services that are appropriate and flexible to user need.

To the best of my knowledge, these doctoral studies represent the first academic research into how women living with HIV in the UK use digital technologies. I am left inspired by how HIV social support service providers continue to modestly yet innovatively design digitally mediated services to suit unfolding user needs.

8.4.2 Contributions involving RQ2: How are digital tools and services designed and used within HIV social support services for women living with HIV in the UK?

In responding to RQ2 I contribute novel insight for interdisciplinary fields relating to HIV Digital Health discourse into (1) how digital tools and services are *developed* by HIV social support service providers (8.2.1), and (2) how these digital tools and services are *used* by women living with HIV in the UK (8.2.2). These insights are further enriched with considerations for how design research activities and

digital innovation projects may be aligned to support these sector-led innovations.

Firstly, insights from my doctoral works shed light on how HIV social support service providers are developed using community-based approaches: considering how the needs of service users may be met using available resources. In response I offer two sets of guidance for aligning design research activities. To support digital HIV intervention projects utilising *existing* digital technologies, designer-researchers should:

- provide guidance in selecting digital tools and functionalities
- conduct research reviewing existing services to explicate usability factors and valued aspects of service provision
- publish empirical evidence of existing digital services to influence policy and support funding bids

To support digital HIV intervention projects creating *bespoke* digital technologies, designer-researchers should utilise Making activities to:

- refine and clarify understanding between interdisciplinary collaborators
- support shared understanding when translating insight into material form

Secondly, insights from my doctoral works illuminated how digital HIV social support interventions for women living with HIV in the UK are informed by user need and use contexts. Participants primarily reported using mobile phones to access digital HIV social support services, echoing recent HIV research in the US (Lockhart et al., 2021). My work enriches this understanding (Simoni et al., 2011), highlighting how the locations that digital social support interventions are used in may be constrained for women living with HIV in the UK due to socioeconomic and cultural factors. In response to these

factors, digital HIV interventions used by HIV social support service providers are designed to:

- be *flexible and inclusive* of diverse user needs and use contexts, allowing users to adapt their use of digital technologies to tailor them to their needs
- extend the *reach and impact* of peer support services, allowing services to reach clients who would be otherwise unable to attend in-person meetings and introduce the benefits of peer support interactions within new contexts
- be *utilised by individuals to provide peer support themselves*, allowing service users to utilise the digital platforms that they receive support on to provide support to others

These insights spotlight how HIV social support service providers are already innovating in their use of digital technologies to amplify the impact of service provision inclusively and sustainably.

As previously expressed (2.1.3.2), current eHealth and HCI discourses involving digital HIV interventions largely do not include digital interventions created and used by HIV social support providers. Insights from this dissertation underline the loss of knowledge this represents, providing empirical evidence to support Beres *et al's* hypothesis that that social support interventions led by HIV service providers are “*more likely to be voluntary, locally-appropriate or sustainable without external support*” (Beres et al., 2017, p. 7). The COVID-19 pandemic has had an immense impact on HIV social support provision, as service users have been forced to rapidly adopt digital tools and services to continue accessing valued support services. Designer-researchers working within stigmatised health contexts should consider evaluating and supporting what work and innovation has already been done by service providers in

response to this pandemic before suggesting bespoke interventions—they know more than you do.

To the best of my knowledge, these doctoral studies represent the first academic research into (1) the development and (2) use of digital technologies for HIV social support service provision for women living with HIV in the UK.

8.4.3 Contributions involving RQ3: What approaches can inform design praxes involving Digital Health tools and services within stigmatised health contexts?

In responding to RQ3 I contribute the methodological foundations of Community-Based Co-Design Praxis (CBCDP), a novel extension to CBPD methodology for ‘expert’ designers working in stigmatised health contexts. In developing and working with CBCDP approach, I contribute worked examples of appropriate design praxes for working with women living with HIV to inform related research fields. I additionally contribute methodological insights into best practices for engaging in design praxis within complex and stigmatised health contexts, presenting this guidance alongside worked examples from this dissertation.

These methodological insights for best practices are summarised as follows:

- (8.3.1) Re-position analytic activities as a collaborative translational process;
- (8.3.1) Supply the means to support collaborators to meaningfully engage in analytic activities;
- (8.3.2) Create tangible representations of work (written, sketches, prototypes) at various points using Making activities;
- (8.3.2) Use Making activities to remain open and flexible to changes in your understanding;

- (8.3.3) Use co-design approaches to empathetically challenge your understanding of both research insights and material translations;
- (8.3.3) Reflect your co-design partnerships by holding shared ownership of research publications and artefacts;
- (8.3.4) Use community-based research approaches to continually attune your design-research activities, refining it to avoid causing harm and offer value for all collaborators;
- (8.3.4) Co-create research outcomes that serve meaningful purpose for all collaborators.

This dissertation contributes methodological foundations and worked examples of CBPD approaches for ‘expert’ designer-researchers working in stigmatised health contexts within the HCI field. I provide examples of how designer-researchers may utilise CBPD approaches and ‘expert’ design praxes while pursuing ethically responsible and emancipatory research, in line with current movements towards a Fourth Wave (Frauenberger, 2019) HCI research paradigm; framing this novel methodological extension to CBPD as CBCDP.

8.5 Reflections on Limitations and Future Work

As a designer-researcher I began this work seeking to understand how my research and design practice could be useful for a marginalised context that I had no lived experience of. Through my PhD journey, I have helped create a national digital information support tool (‘Looped in’) with the National AIDS Trust; co-authored a paper in an International HIV journal alongside a peer-run HIV organisation (Hay et al., 2020); and co-designed a zine with women living with HIV that was subsequently used by a local service provider. Furthermore, I have had the invaluable opportunity to listen and learn from the amazing women I have had the privilege to

collaborate with. Whilst I feel fulfilled by this work and its impacts, I know there is still so much more work to be done.

Women living with HIV in the UK deserve better than anything this doctoral project could deliver. They deserve to be valued by their government and have their social support services funded accordingly. They deserve to feel safe and respected by their doctors, partners, family, and communities. They deserve to feel sexy and confident. My PhD studies barely touched upon any of these topics, and they deserve further exploration and response than this work could provide. Additionally, more voices and experiences should be represented within work conducted in the UK, including but not limited to young women, trans women, bisexual, pansexual, and lesbian women, and non-binary people living with HIV. This doctoral work lacks representation of these voices and their plurality of experiences and needs, and they deserve to be heard. There is so much work still to be done.

As a qualitative programme, my work has focused on delivering a rich picture of the voiced expressions and experiences of groups of individuals; it was not my aim to deliver statistically representative findings. My approach and choice of methods was purposeful: there is limited research on the use of digital social support interventions for women living with HIV in the UK and limited research on what those interventions even are. However, previous research (2.1.3) has repeatedly highlighted the importance and precarity of social support interventions for women living with HIV in the UK. It was important for me to provide a rich and nuanced picture of why these services are designed and used in particular ways, in order to highlight the personal impact and ingenuity of HIV social support service provision. The small scale of the qualitative research works undertaken within my doctoral programme means that my findings

may not necessarily be generalised to other groups of people living with HIV, or other settings. However, the depth of context provided through this programme of work will allow others to ascertain if there are transferable insights.

The geographical location of my doctoral research has also shaped my work and its respective insights. My work predominantly involved women residing in urban areas of the North East, London, or South of England, and HIV social support service providers based in these regions. My doctoral work is therefore not representative of the geographic diversity of health inequalities and other divides across the UK. Further research is needed to illuminate the gaps in knowledge on the experiences of women living with HIV in other areas of the UK, especially rural areas. Furthermore, it is important to note that the geographical location and contextual focus of my doctoral work limits its transferability to other geographic settings, including Sub-Saharan Africa where the majority of women living with HIV globally live (UNAIDS, 2020).

Additionally, I configured a unique approach in my PhD studies by considering how 'expert' designers may use their design praxes within CBPD projects to co-create communicative artefacts for stigmatised health contexts. Review of Co-Design research in health has highlighted that many projects falter when it comes time to use insights to inform new services or intervention because professional designers are not involved within research projects (Donetto et al., 2014). Similar concerns have been raised by Manzini (2016), who has noted how designers have been relegated to 'sticky note' facilitators, rather than contributing their expertise within many co-creative processes. The Digital Health discourse in HCI could utilise Design expertise (and 'expert' designers) to better understand how insights may inform the *material form* of Digital Health interventions.

Doing design research helps define these translations while contributing additional insight through what arises during this translational process. Although the methodological focus of this doctoral work on 'expert' design praxes limits its transferability, I intend to build a case to address the current need for more design praxis within HCI Digital Health research discourses.

This doctoral project represents the first academic work of its kind into the use of digital technologies by women living with HIV in the UK; in the wake of the COVID-19 pandemic, it will not be the last. Whilst my studies were conducted before the pandemic, the time of publishing my thesis makes it very significant. Digital adoption and service innovation has proliferated within HIV service providers across the UK in response to the pandemic, as in-person services were paused to protect their clientele as a vulnerable population. This pivot is likely to be a more enduring change as it fits within larger movements towards digitally mediated healthcare services within the UK (NHS, 2021). As service provision moves to more mobile or hybrid models, this dissertation offers insights to advise future work in this space.

Firstly, Digital Health models shift financial cost and access consideration to the user, which may amplify existing health inequalities for socioeconomically marginalised users. Women living with HIV should be afforded access to in-person services and resource to support digital technology use whenever possible, to allow services to remain accessible for those who need them the most.

Secondly, in the wake of COVID-19, HIV social support service providers have utilised digital tools and services in ways which operate within limitations of available resources for the needs of their

clients. Researchers considering conducting research into digital HIV interventions should consider accessing the work already done by service providers, to learn what works and why, before seeking to implement bespoke interventions. There is so much still to learn from HIV service providers as they continue to co-develop new tools and resources, and designer-researchers within the HCI field are well positioned to support these works.

Thirdly, insights from my doctoral work suggest some common practices and service design elements between digital HIV peer support service providers (8.2.2). Further research is needed to shed light on the range and commonalities of digitally mediated HIV peer support service design in order to inform best practices for service providers. National standards for peer support service provision (Positively UK, 2017) should also be expanded to include best practices for digitally mediated peer support.

Lastly, the digital interventions noted in this dissertation worked because they afforded *individual control* over how digitally connected a woman was to her peers. Emerging mobile and hybrid models of peer support services should consider how they may afford this control to users, especially those who are newly referred, in order to support key values of 'trust' and 'respect' within digital service provision.

My project is situated between multiple discourses, reflective of the reality of HCI Design research in the early days of Fourth Wave (Frauenberger, 2019) HCI discourse. This paradigm shift calls for designer-researchers to consider the worlds co-created around us, to consider what we already have, and to take ethical responsibility for what we decide to do with it. This purview should not be limited by previous conceptualisation of what counts as 'novel innovation' in

this field. We have so much more responsibility for the worlds that we make than is currently accounted for in Digital Health, and this is no time to be cynical—there is so much space for positive impact. I am excited about the future of Fourth Wave (ibid.) Design-led HCI as a *craft*, a way of making with respect for the people and materials around us, to lead in this next chapter. Let's grow forward, together.

9 Conclusion

Communication Design has long affected conceptualisations of HIV. Digital Health interventions offer a new medium for communication designers to apply their expertise. As Fourth Wave (Frauenberger, 2019) HCI takes on the challenges of our contemporary world, and our ethical responsibility to respond, Communication Design praxes offer valuable guidance for designing in complex and stigmatised health contexts.

Digital technologies are only going to pervade further into daily life in the wake of COVID-19, becoming more normalised and mundane. While socio-materiality is broadly understood within Communication Design discourse, it is only now being introduced into the HCI field. It is crucial that designer-researchers working in HCI understand and take responsibility for how and what digital artefacts communicate to the world through their inherent socio-materiality. As a communication designer I formulated CBCDP, a novel extension of CBPD, in order to draw upon previous participatory Communication Design approaches to design research in the context of HIV (And Also Too, 2015; Bennett et al., 2006; Wizinsky, 2019); positioning this approach in relation to existing HCI discourses in order to translate community-based Communication Design praxes into a new field. CBCDP offers guidance for how digital artefacts could be collaboratively made within complex contexts affected by stigmatising beliefs, allowing for normative beliefs to be called into question and challenged through the design process. This guidance makes CBCDP applicable to 'expert' designers working in a broad range of HCI discourses impacted by negative beliefs, including those involving stigmatisation, invoking feelings of embarrassment or shame, or involving marginalised communities. The utility of CBCDP may be particularly applicable for designers working in marginalised

Digital Health contexts in the HCI field, given the existing evidence supporting community-based approaches in Health research (Coughlin et al., 2017).

Critically, it should be noted that CBCDP is meant to inform ‘expert’ design praxes; review of Co-Design studies in healthcare has shed light on how the absence of Design professionals within research teams has stalled research insights from being applied within actual health interventions and services (Donetto et al., 2014). This doctoral project underscores the value of methods and expertise drawn upon by ‘expert’ designers, providing worked examples of the unique insights and outcomes that design praxes support when applied within academic research. **‘Expert’ designers should be involved within interdisciplinary research projects applying research insights to designed forms**, but this is arguably not common practice within current academic Digital Health discourses. As HCI discourses move towards a Fourth Wave (Frauenberger, 2019) research paradigm, designer-researchers are well positioned to establish the value of ‘expert’ design praxes through the design of artefacts and interventions for Digital Health applications. CBCDP offers guidance for ‘expert’ designers seeking to do so with ethical responsibility for the processes and products of their praxes within these spaces.

As a communication designer working within the HCI field using a CBPD approach, it is also key to highlight that true coalition and collaboration are crucial when seeking to understand the experiences of others. The development of this doctoral thesis has been informed and guided by the daily lives and work of women living with HIV in the UK and their social support service providers.

- Through the voiced experiences of my participants, I have been able to contribute knowledge on how financial, digital

confidence, and privacy and security factors may impact digital technology use by women living with HIV in the UK; and how HIV social support service providers have been modestly, yet innovatively, developed digitally mediated services in response.

- Through collaborative research with HIV social support service providers, I have been inspired by the ways in which they have designed their digitally mediated services to suit their client's unfolding needs, providing insight on how these choices help amplify the impact of service provision.
- In reflecting on my experiences in working alongside HIV social support service providers, I have identified ways that designer-researchers may usefully align design research activities to support appropriate and sustainable digital innovation.
- And through collaborative projects, I have provided worked examples of using community-based approaches within an 'expert' design praxis, shedding light on how the values of peer support may be crafted into the socio-materiality of design artefacts through collaborative design praxes.

These works contribute insight and example to interdisciplinary discourses involved in the design of digital HIV social support interventions; and offer insight for respective critical discourses in Digital Health, HCI, and Design involved in collaborative design projects within marginalised contexts. It is crucial, however, that these contributions are understood to have been made possible by working in coalition and collaboration with my participants and collaborators. I would be lost without the grace that my collaborators and participants have extended to me as a newcomer seeking to understand, translate, and represent their lived experiences. I began my doctoral project with the motivation to make it as useful to women living with HIV in the UK as possible within the limits of my abilities,

and yet I am left indebted to the generosity and camaraderie of everyone I have worked with.

Through my work I have navigated a complex and marginalised research context and multiple complex interdisciplinary discourses. Through it all, my guiding stars have been those living with HIV and those who specialise in working in dialogue with that lived experience. It is crucial that marginalised knowledges are understood as intended by the marginalised, rather than being independently extracted, repackaged, or otherwise colonised by others. Doing and presenting research in a context which has historically unequal relations of power between research and experts by lived experience has consolidated my understanding of the role and responsibilities of designer-researchers in translating and sharing the wisdom of others. I wrote this dissertation, but I am not the source of wisdom that fuelled its insights. This wisdom came from people living and working, as they do every day, to navigate, survive, and thrive in a complicated and unequal world. More than the empirical insights or worked examples, I hope my work and its outcomes have been useful in recognising the importance of setting one's course by the guidance of those that know the way. I have deepened my understanding of the importance, value, and responsibility of working with others in marginalised contexts through my doctoral research, which has in turn has led me to value my trained expertise as a communication designer working in interdisciplinary contexts. Although I may not know the way, I know that my work may be useful for the journey.

Negative beliefs about HIV continue to negatively affect the lives of people living with HIV globally, including women living in the UK. HIV stigma is arguably a ghost that exists in beliefs and actions—it exists because it haunts us, and we continue to understand and impact our

reality in relation to it. As designers and academics, it is our responsibility to consider how our work (be it process, artefact, or published words) may bolster or challenge the spectre; it lives in the shapes we give it. Rather than continue to try and outline a ghost with no shape, it is far more useful to, instead, as Alice Welbourn outlined in Chapter 6.5, “[start] with a positive vision and [consider] how to reach it”. We create the futures we want by building towards them, and it is only by co-creating those futures, growing towards them together, that they will come to exist. The ghost of HIV stigma is alive today and continues to haunt and harm us, however we are capable of wresting control of it by changing the practices, things, and words through which it is conceptualised, represented, and responded to. It’s about time we put this knowledge into practice rather than chasing a ghost, as it’s only through practice that we may seek to exorcise it.

This thesis documents the first academic research into the use of digital technologies by women living with HIV in the UK, and it will not be the last. I hope that the publication of this work will help push towards a possible future—one in which community-based research methods are more widely adopted for HCI Design research involving marginalised populations; where ‘expert’ designers are more regularly involved within academic Digital Health research and discourse; and where the vibrancy and ingenuity of women living with HIV and their social support service providers is better represented within academic discourse, policy, and funding. I look forward to the work to be done together, alongside each other, towards that day.

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A Ethical Approval

Ethical approval was granted for my first empirical research study (Blue Sky Trust: Focus Group Discussion, Chapter 4) by the departmental Ethics Committee at Northumbria University [Ref: 9885] on 2 July 2018. Proof of this confirmation and related documentation is provided in Appendix C.1.

Ethical approval was granted for my second empirical research study (4MNetwork: Collaborative Interview Study) by the departmental Ethics Committee at Northumbria University through an amendment to my original ethics application [Ref: 9885] on 10 January 2019. Proof of this confirmation and related documentation is provided in Appendix E.1.

Ethical approval was granted for my third empirical research study (Blue Sky Trust: Zine Workshops) by the departmental Ethics Committee at Northumbria University through an amendment to my original ethics application [Ref: 9885] on 17 October 2019. Proof of this confirmation and related documentation is provided in Appendix F.1.

B Developing a Visual Design Identity for Study Materials

I conducted sensitising research into the graphic design of HIV health information documentation prior to my first research study. This visual research is included within Appendix B.1. I then used this analysis to inform my own graphic design experimentation, producing the visual identity I would use for all printed materials used in my subsequent research studies (Appendix B.2).

B.1 HIV Information Materials Research

HIV information materials begin on the next page.

Font

Simple san-serif fonts

Helvetica, Arial, etc.

Little graphic design creativity

Clear and direct

Easy to read

High contrast

Every piece of printed material reviewed almost exclusively used simple, san serif fonts. This typography would be offset with different weights (e.g. bold), or uses of colour, but would rarely change beyond those two factors. This may have been done due to the clear nature of these fonts, allowing them to communicate information clearly and directly in a clinical context, however they were also used in non-clinical items (e.g. Sophia Forum business card). Another benefit of this design feature is the high contrast use of the font, as it allows users at a variety of ages and abilities to easily access the written content.



Colour

Bright, bold colours

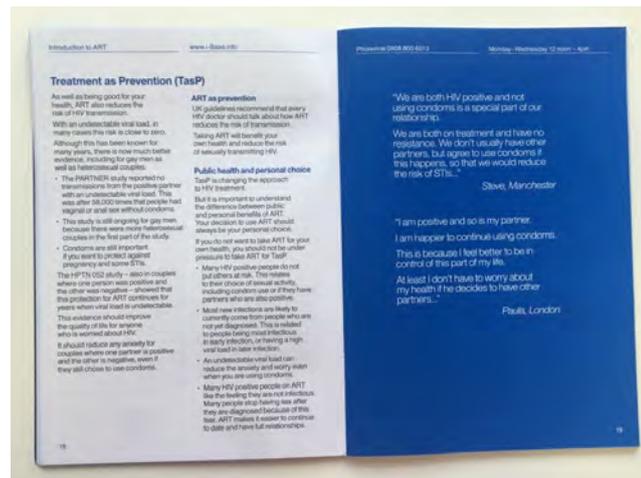
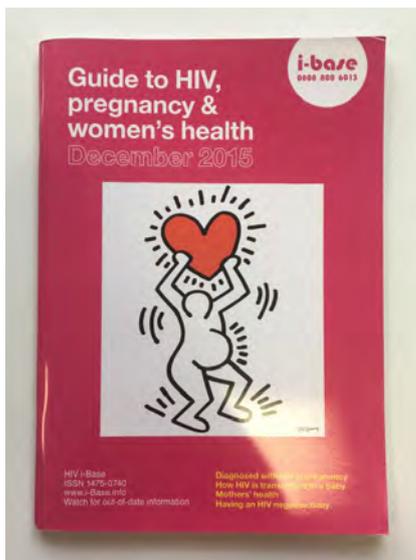
Corporate colour schemes

Common use of red (HIV colour)

Often offset against white background

High contrast

Saturated colours are used in all of the materials reviewed. Bright colours are usually limited to a maximum of three per publication, with many materials using a simple 1-2 colour palette. Bright colours are also offset with uses of white to tone down the vibrant colours, which also aids in creating high contrast for easy reading of the written materials. If multiple colours are used, the combination gives a corporate design effect rather than an artistic one; a commercial design mainly servicing to communicate information rather than emotion.



Photography

Focus on diversity

Usually in non-profit/service documents

Rarely used in clinical/medical documents

Usually images of human faces

Hands holding things another theme

Photography was often used within the HIV printed materials reviewed, especially in those published by non-profits/support groups. Photos often were used to show a diversity of user types, featuring different genders, ages, and/or ethnicities. Another common theme in photos was a single hand (in this sample, a Caucasian hand) holding some sort of item related to HIV (e.g. medication, a red ribbon). The only outlier in the sample was one side of the Sophia Forum business card, which showed a series of lace garments hung outdoors on a drying line. This goes against the heavily corporate imagery of other materials, focussing on a personal and feminine approach.

OUTLIER: SOPHIA FORUM BUSINESS CARD

EXAMPLE: HANDS HOLDING THINGS



Illustration

Common HIV icons used (e.g. blood)

Very geometric; smooth elements

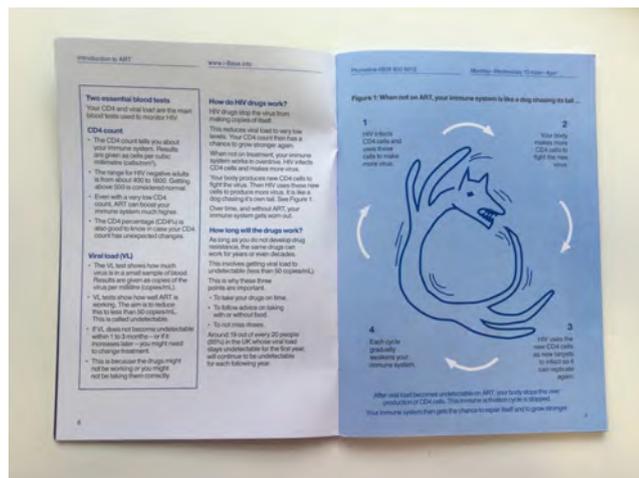
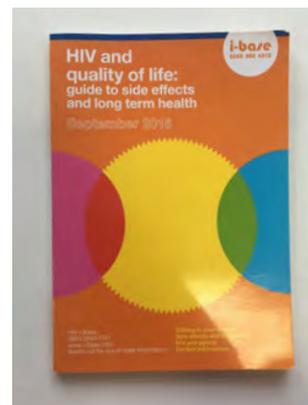
Rarely handmade illustration

Handmade illustration has outline only

Line and colour mainly used

Always flat or 2D

Illustration was more commonly used in more corporate and/or clinical publications within the sample. When used, graphics are largely flat, 2D images using saturated colours and smooth lines. When a more handmade aesthetic is used, drawings are limited to line art only. HIV-related iconography, such as blood, plus signs, and red ribbons, as well as general infographic images, are employed frequently to directly illustrate the content of the accompanying text. There is a design opportunity presented due to this lack of graphic design for more interesting and engaging visual explorations.



Logos

Text logos most common

No icon-only logos sampled

Text/icon logo second most common

i-base common publisher

Unique san serif common for logos

Logos used in the HIV publications within the sample were almost entirely text only logos. These logos usually used a more unique san serif font, although few did use bold serif fonts as well. Only two logos, Sophia Forum and MSD, used both an icon and text in their logo. Upon review of the publication logos, most publications were published by, or in part by, i-base, a treatment activist group with a history of editorial work. This fact may add to the coherence of common design traits among the sampled publications, despite them being the predominant publications available in the outlets sampled (Doctor's office, non-profit event location, non-profit office).



Physical

Booklets and pamphlets in standardized sizes

Accordion booklets half an A3

Business cards standard

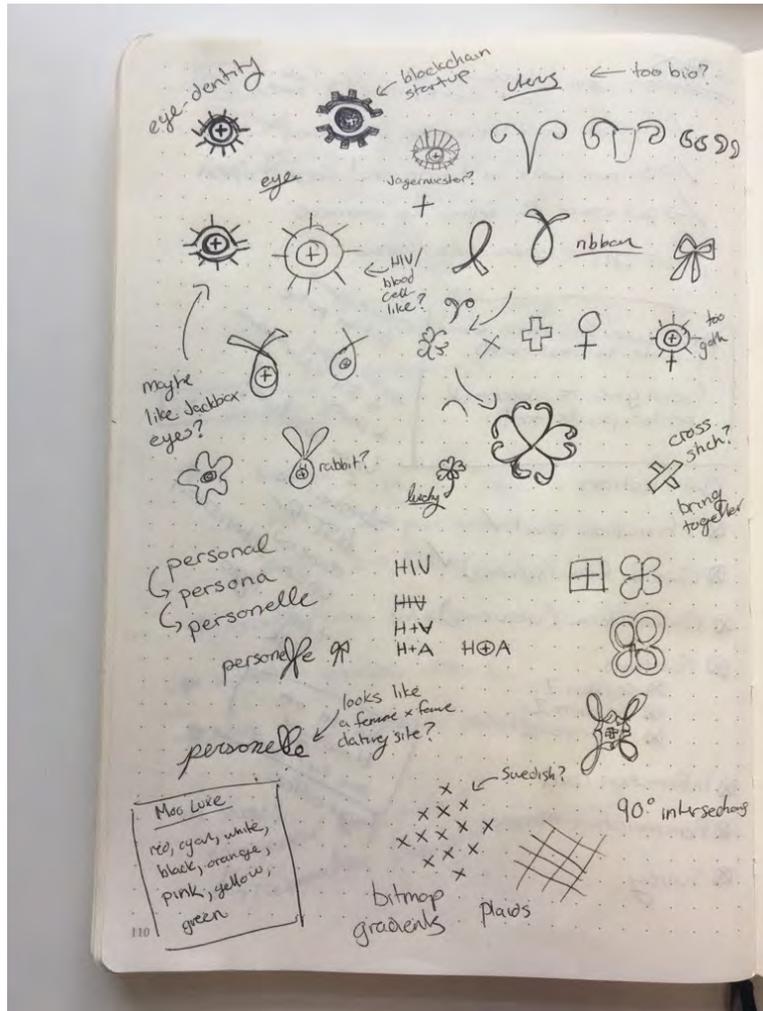
Mixture of gloss, semi-gloss, and matte paper

Light to mid-weight paper used

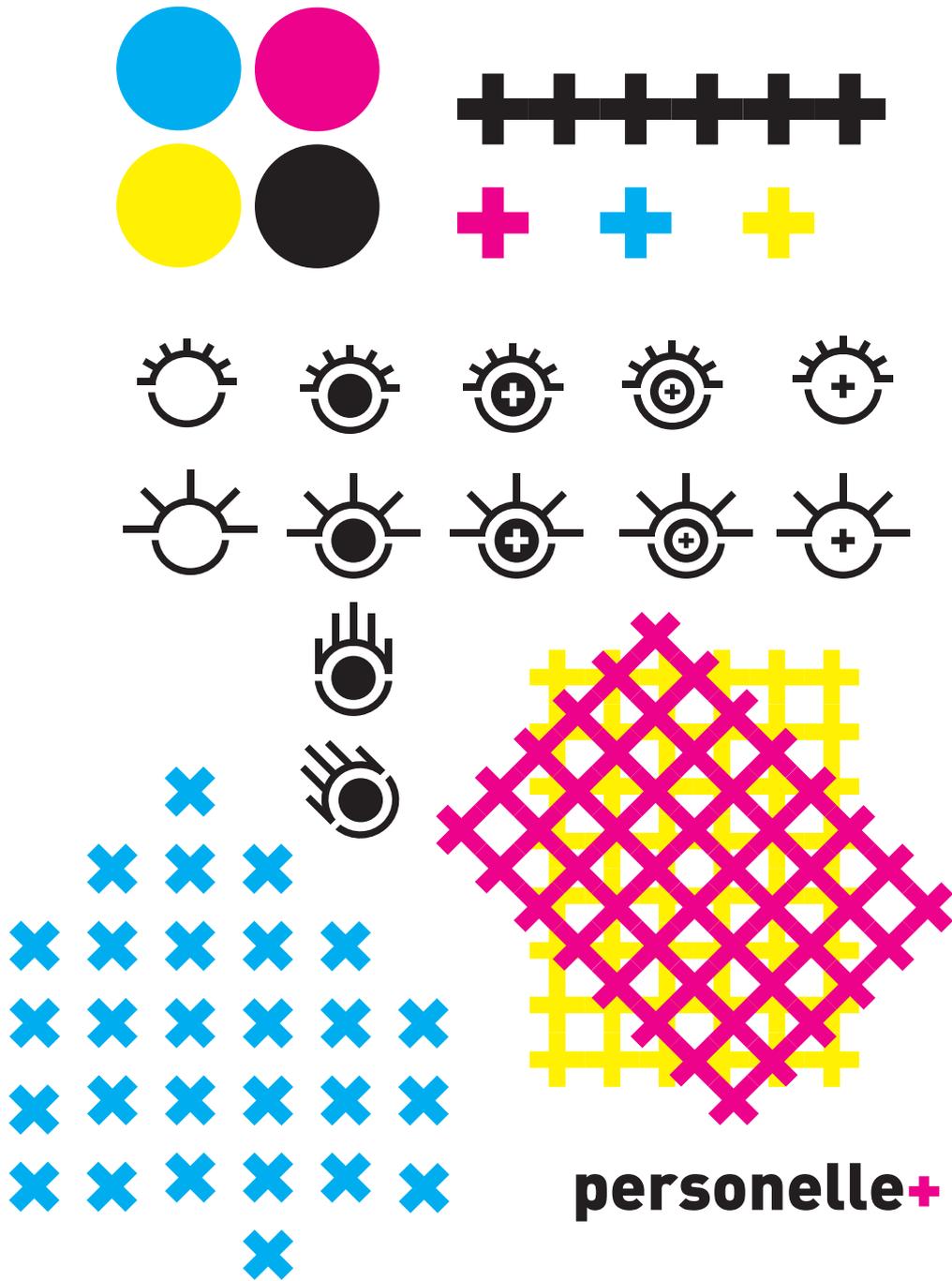
All materials seem to be printed in standardized sizing. This may be cost or time-saving measures, as both time and money is restricted for many HIV support services and/or areas of medical support. There seem to be no standard for paper type, although the sample only used standard gloss, semi-gloss, or matte paper finishes. All paper weights within the sample do seem limited to light or mid-weight papers, which may be another factor of cost-saving through standardized material sourcing. While many of the sampled materials do have a paper weight and finish befitting a mid-quality printed product, the combinations do also present themselves as being mass-produced, economic printing jobs.



B.2 Project Branding Experiments



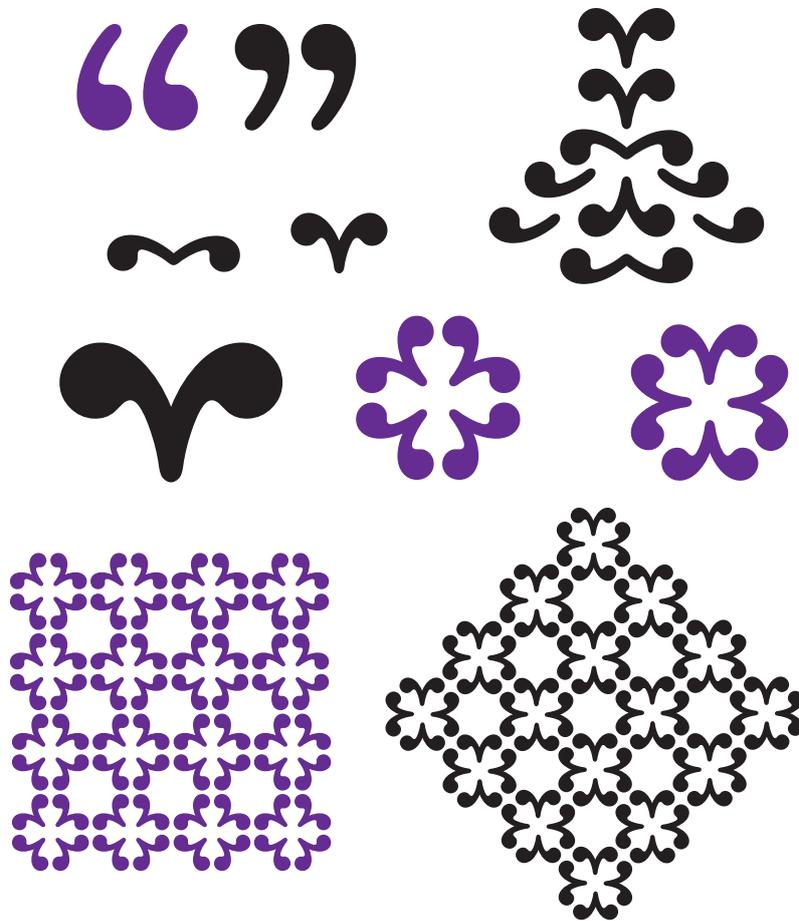
• Sketching •



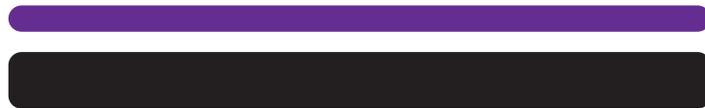
personelle+

IDEA #1

Digital meets Print • Positive • Bright • Feminine
Individual • Graphic

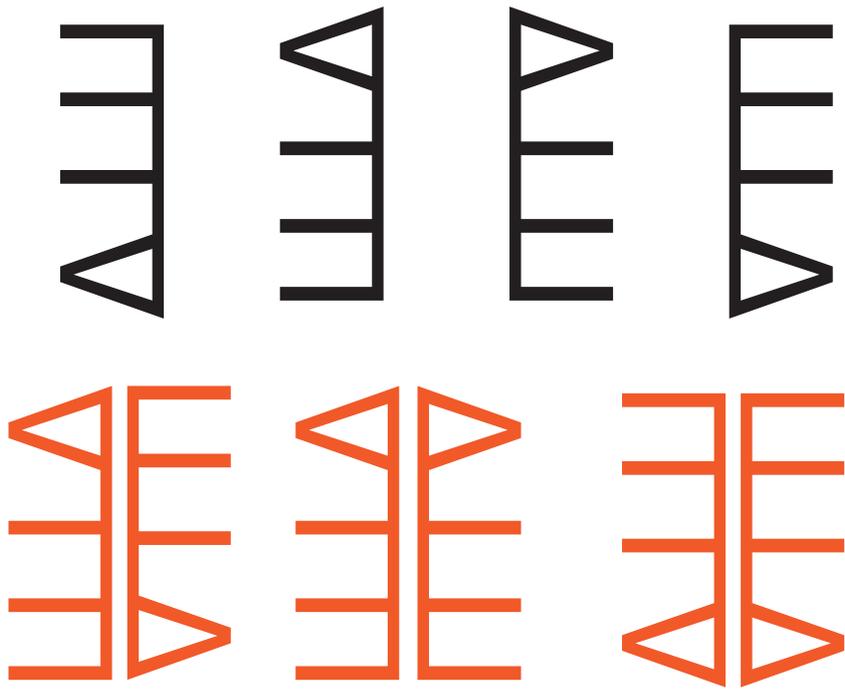


personelle.



IDEA #2

Mature • Written • Book • Woman • Classic • Story • Floral



IDEA #3
Health • Modern • Code • Ancient • Unisex • Tech • History

C Blue Sky Trust: Focus Group Discussion (FGD)

C.1 Ethical Approval

Ethical approval was granted for my first empirical research study (Blue Sky Trust: Focus Group Discussion, Chapter 4) by the departmental Ethics Committee at Northumbria University [Ref: 9885] on 2 July 2018. Supporting documentation is provided within the subsequent subsections.

Research Ethics: Your submission has been approved

EthicsOnline@Northumbria <EthicsOnline@Northumbria>

Mon 02/07/2018 10:22

To: kiersten.hay <kiersten.hay@northumbria.ac.uk>

Dear kiersten.hay,

Submission Ref: 9885

Following independent peer review of the above proposal*, I am pleased to inform you that **APPROVAL** has been granted on the basis of this proposal and subject to continued compliance with the University policies on ethics, informed consent, and any other policies applicable to your individual research. You should also have current Disclosure & Barring Service (DBS) clearance if your research involves working with children and/or vulnerable adults.

* note: Staff Low Risk applications are auto-approved without independent peer review.

The University's Policies and Procedures are [here](#)

All researchers must also notify this office of the following:

- Any significant changes to the study design, by submitting an 'Ethics Amendment Form'
- Any incidents which have an adverse effect on participants, researchers or study outcomes, by submitting an 'Ethical incident Form'
- Any suspension or abandonment of the study.

Please check your approved proposal for any Approval Conditions upon which approval has been made.

Use this link to view the submission: [View Submission](#)

Research Ethics Home: [Research Ethics Home](#)

Please do not reply to this email. This is an unmonitored mailbox. If you are a student, queries should be discussed with your Module Tutor/Supervisor. If you are a member of staff please consult your Department Ethics Lead.

C.2 Study Documentation

C.2.1 Discrete Contact Cards

Contact cards were designed to be discrete, with no visible HIV information. These were given to participants at various points (introductions, focus group discussion).



C.2.2 Information Sheet

The final information sheet was distributed in a folded brochure, pictured belloved. Following these images is the full written content of the brochure.



Written content of the information brochure

Women and Technology

Hello!

We will be coming to an upcoming peer support meeting at Blue Sky Trust, and we would very much like you to help us with our research for a project based at Northumbria University.

This will involve us coming during the second hour of a peer-support meeting and talking in a group discussion about your experiences with peer support services and your everyday use of technology. We want to understand more about what peer support services mean in your life, as well as what sort of technologies you use in your day-to-day lives.

Who are we?

This project is led by Kiersten Hay, a PhD student at Northumbria University in the Design Department, who will be joined by Dr. Abigail Durrant, a professor within the Design Department at Northumbria University. We are design researchers who work in the area of human-computer interaction (HCI), and we are researching how digital tools could potentially help women living in the UK.

Why are we doing this?

We believe that digital tools may be able to assist women living in the UK increase their wellbeing. To understand more about how this could be done, we want to hear from women like you as to what technology means, or doesn't mean, in your daily life.

What will you be asked to do?

The researchers will lead a casual discussion in the second half of the meeting, covering topics of peer-support experiences, technology use, and privacy. This discussion will last 45-60 minutes. You are welcome to

Speak as much or as little as you like during this conversation—we are here to learn from you!

What sort of technologies will be discussed?

This is up to you! This could include anything from cell phones and Internet use to metro passes and smart home meters. We want to understand what technologies you use on an average day, what you use them for, how they impact your life, and what technologies you may want to use in the future.

What data about me is being collected?

As a part of this research we will ask you to complete an anonymous short personal data sheet that will include your age and ethnicity. This data will be used to give a general overview of the people who took part in the session. This data will be kept securely and anonymized.

What is the legal basis for processing personal data?

We are collecting personal data within this study, with the legal basis for processing the personal data required for the purposes of this study being that the research is being conducted in the public interest. Special category personal data (e.g. ethnicity) in particular is being collected, as it is necessary for scientific and historical research purpose. This means that we will be comparing this data (which will not be traceable to you) to previous studies.

Who are the recipients or categories of recipients of my personal data, if any?

Personal data will not be accessed or seen by anyone other than the research team at Northumbria University, and will remain inside the EU. While some parts of anonymised transcripts may be used in academic publications, all individual identifying personal information (such as your name) will be removed to maintain privacy.

Do I have to do this?

Deciding not to take part, or leaving the study at any time, will not affect your right to come to meetings at Blue Sky Trust. If you don't wish to join in the session you are also welcome to attend the meeting at Blue Sky Trust taking place before our session, and then leave once the main session has been completed and before our research session begins.

Will you be paid for doing this?

Yes. We value your time and insight, and will be giving each participant a £10 Love2Shop gift voucher for their participation. You will still receive the voucher if you choose to remove your data from the study during or after the session has been completed.

Will the information you give be confidential?

Yes. Everything discussed during the meeting will be confidential. We would like to record audio of the discussion to make sure we remember everything said, however this information will be securely stored and all audio files will be deleted once an anonymized transcript of the discussion has been made. While some parts of these transcripts may be used in academic publications, all individual identifying information (such as your name) will be removed to maintain privacy.

What if I don't want to have my voice recorded?

This is completely fine. If anyone does not wish to be recorded, we will not record the session and instead take notes during the discussion. Any notes will also be anonymised and kept securely. We will only record the session with the entire group's consent.

Will you be able to change your mind about taking part?

Yes, you can withdraw at any point before, during, or after the session. You can let us know in person or within 15 days of the session using the

contact information provided at the bottom of this sheet and we will destroy all records of anything you have said.

What are the potential benefits of participating in this?

These sessions are the first part in a 3-year study looking into the use of technology in the lives of women living in the UK. We hope to continue working closely with Blue Sky Trust to develop and design potential tools to help in this process based on the information we receive from research activities like these sessions. Participating will mean that your voice is heard and responded to within this context, and will be able to influence the development of new tools that develop through this research.

What are the potential disadvantages of participating in this?

These sessions have the potential to cause some emotional discomfort if difficult topics arise within the conversations, such as personal concerns around privacy. While these topics will only be posed openly (e.g. What does privacy mean in your daily life?), you will not be required to respond if you are in any way uncomfortable.

Support and guidance will be available through a resource pack (containing help-line numbers and health promotion materials). A peer-support facilitator from Blue Sky Trust will also be available during the session(s) should the discussion raise any issues you are concerned about.

How will my data be stored, and how long will it be stored for?

Any audio data will be collected using an encrypted audio recorder before being moved to an encrypted hard drive for transcription by the lead researcher. Once the transcription is complete and anonymised all audio files will be deleted.

Audio transcriptions, survey data, and/or observational notes will be securely stored on an encrypted hard drive. This data will be stored for

the duration of the study, +7 years [2027], after which it will be deleted. All data will be stored following University guidelines and GDPR regulation.

How will I be kept updated on the outcomes of these sessions, and of the research project in general?

Findings from these sessions will be summarised and sent to Blue Sky Trust for dissemination during regularly scheduled peer-support meetings, and/or as deemed appropriate by Blue Sky Trust staff. The lead researcher can also be contacted anytime using the contact information provided at the end of this information sheet.

What are my rights as a participant in this study?

As a participant in this study, you will have:

- A right of access to a copy of the information comprised in their personal data, which can be done by contacting the lead researcher up to 15 days after the completion of the session;
- a right in certain circumstances to have inaccurate personal data rectified;
- and a right to object to decisions being taken by automated means.

If you are at any point dissatisfied about the University's processing of personal data, you have the right to complain to the Information Commissioner's Office. This can be done online <https://ico.org.uk/make-a-complaint/>, or by calling their helpline at 0303 123 1113.

What happens next?

If you are still happy to take part, simply attend the peer-support meeting at Blue Sky Trust on July 3, 2018, and we will begin our session at 13:00. The session will last approximately one hour.

On the day of the session, you will be asked to sign a consent form before the start of the discussion, which will include information of how your information will be stored, secured, and anonymized.

Thank you for reading this information.

If you have any questions, comments, or concerns about the session, your data, or the research project, please contact Kiersten. She will also be in attendance at the start of next week's meeting should you have any questions you wish to ask in person.

Lead Researcher

Kiersten Hay (Principal Investigator)
Northumbria School of Design
Room 120, Squires Building, 2 Sandyford Rd
Newcastle upon Tyne, NE1 8SB
Email: Kiersten.hay@northumbria.ac.uk

Data Controller: Northumbria University

Duncan James
Data Protection Officer at Northumbria University
dp.officer@northumbria.ac.uk

Northumbria University Research Ethics

Jennifer Stergiou
Director (Research and Innovation Services)
Email: jennifer.stergiou@northumbria.ac.uk
Telephone: 0191 227 4908

C.2.3 Renumeration Form

Remuneration Form

I confirm that I have received a £10 Love2Shop voucher for my involvement in a study.

Participant Name (please write):

Participant Signature:

Date:

Researcher Name: Kiersten Hay

Researcher Signature:

Date:

C.2.4 Debrief Sheet

Women and Technology: Debrief Sheet

Thank you for taking part in our research on women and technology.

At this time, we will go over (1) what this research is about; (2) why we worked with you today; (3) how to access your data from this study if interested; (4) how long data from this study will be kept for; and (5) your rights to withdraw your data should you choose (including the time limits and how to do so).

Contact information is also listed at the bottom of the page should you wish to contact the lead researcher or make any ethical comment or complaint to Northumbria university.

What is this research about?

We are researching the use of peer-support services for women in the UK such as yourself to better understand why these services are so valued.

In addition, we are investigating the use of technology by women in the region to better understand how you use technology, what you use it for, and what kind(s) of technologies you use on a regular basis. This is to inform the design and development of potential digital technologies to help increase wellbeing.

Why did we work with you today?

Data on women such as yourself, living in the North East of the UK, are very limited, and so we wanted to know your thoughts on these topics in order to best inform technologies designed for you. We worked with you today in order to learn more about your experiences and opinions in order to inform the development of our research moving forward, as well as to get a broader understanding of your daily lives.

How do I find out about the results of today's session?

Findings from these sessions will be summarised and sent to Blue Sky Trust for dissemination during regularly scheduled peer-support meetings, and/or as deemed appropriate by Blue Sky Trust staff. The lead researcher can also be contacted anytime using the contact information provided at the end of this information sheet.

How do I access my data from this research?

If you would like to access your data from this research (e.g. a transcript of what has been said in today's session), please contact the lead researcher, Kiersten Hay, using the contact details provided at the bottom of this sheet (email or by mail). Should you have any issues contacting us through these methods, please reach out to Blue Sky Trust to contact us on your behalf.

How long will my data be kept for?

All data will be kept securely, stored in an encrypted hard drive for 7 years after the study's completion, after which time it will be deleted. All data will be stored following University guidelines and GDPR regulation. All audio data (e.g. session audio recordings) will be deleted once they have been transcribed and anonymized (e.g. all names removed and replaced with pseudonyms/codes). Audio data will never be played to anyone outside of the research team.

Personal data will not be accessed or seen by anyone other than the research team at Northumbria University, and will remain inside the EU. While some parts of anonymised transcripts may be used in academic publications, all individual identifying personal information (such as your name) will be removed to maintain privacy.

My rights to my data

Should you wish to withdraw your data from this study, you can let us know in person or within 15 days of today's session using the contact

information provided at the bottom of this sheet (email or by mail). After this point all data will be anonymized (e.g. all names and identifying information removed from the transcripts and original audio files deleted), and we will be unable to remove your specific data. Should you have any issues contacting us through these methods, please reach out to Blue Sky Trust to contact us on your behalf. If contacted, we will then destroy all records of anything you have said during today's session. Withdrawing your data will not affect your remuneration, that is yours to keep, or your access to Blue Sky Trust and/or other support services.

If you are at any point dissatisfied about the University's processing of personal data, you have the right to complain to the Information Commissioner's Office. This can be done online [<https://ico.org.uk/make-a-complaint/>], or by calling their helpline at 0303 123 1113.

If you have any questions/concerns about the protection of your data at Northumbria University, please contact the data controller contact, Duncan James (listed below).

If you have any questions/concerns/complaints about the ethics of this study, please contact Jennifer Stergiou (listed below).

Contacts

Lead Researcher

Kiersten Hay (Principal Investigator)
Northumbria School of Design
Room 120, Squires Building, 2 Sandyford Rd
Newcastle upon Tyne, NE1 8SB
Email: Kiersten.hay@northumbria.ac.uk

Northumbria University Research Ethics

Jennifer Stergiou
Director (Research and Innovation Services)
Email: jennifer.stergiou@northumbria.ac.uk

Telephone: 0191 227 4908

Data Protection Officer at Northumbria University

Duncan James

dp.officer@northumbria.ac.uk

C.2.5 Consent Form

Consent Form: Women Living with HIV and Technology

Session Date:

Lead Researcher: Kiersten Hay

Supervisor: Abigail Durrant

I agree to take part in this research and confirm:	Initials
1. I have read and understood the information sheet about taking part in this discussion.	
2. I agree to take part in this discussion, with the understanding that I am not required to contribute at any point if I do not wish to.	
3. I have had an opportunity to ask questions and discuss this study and I have received satisfactory answers.	
4. I understand that all paper and/or electronic research data will be stored securely (password protected for electronic data; in locked storage for paper data) at Northumbria University.	
5. I agree that the anonymized data that I contribute will be archived at Northumbria University and may be reused by other researchers in the future.	
6. I understand that the information collected for this study will only be used for research purposes, and that my consent is conditional upon Northumbria University complying with its duties and obligations under the General Data Protection Regulation 2018.	

I give my consent to this discussion being audio recorded and transcribed, with any audio files being deleted once transcription has been completed with all identifying information removed to protect my privacy.

Please check the box below if you consent to audio being recorded of this session

Participant's Name [in block letters]:

Participant's Signature:

Researcher's Name: KIERSTEN HAY

Researcher's Signature:

Date:

C.2.6 Topic Guide

Session 1 Topic Guide

Introductions [10 minutes]

- Introduce myself and any other researcher(s) there
- Explain the research we're doing, how this session will be used
- Explain what's being done how (recording), and the consent forms
- Address any questions and/or concerns
- Pass around consent forms and survey (clipboards)

Icebreaker [10 minutes]

Purpose: to have everyone introduce themselves/speak and get a bit more comfortable, while also allowing time for the survey to be completed.

Ask each person to introduce themselves (if appropriate; people may want to remain anonymous) and say a little on what they get out of being connected to the Blue Sky Trust.

Main Session [35 minutes]

Discussion will include the following questions in a semi-structured format:

4. What do you value about this (BST) kind of peer-to-peer setting?
 - a. Are there other ways that you achieve these values?
 - b. What is it about these things that you value (e.g., what is it about "friendship"?)
 - c. How else is this facilitated (e.g., how else do you experience friendship)
 - i. How does technology help (if at all) with this instance as well?
 - d. How could technology aid these values?
5. What kind(s) of technology do you use in everyday life? [provide a visual list/prompt to review list in survey]
 - a. Discuss as an open conversation, or potentially go around the circle is people are quieter
 - b. Could lead to people saying they don't use technology very much; if so, enquire about why, potentially learn about fear/concerns from this
6. What sort of privacy concerns do you have (general)?
 - a. Why? (May come up in prior question)
 - b. Do you have any privacy concerns about technology?

c. How can technology help and/or make these concerns worse?

Wrap up & Debrief [5 minutes]

- Thank everyone for their time
- Give point form overview of what's been covered
- Remind on how the findings will be applied and distributed to them later
- Remind on how to get in touch if they want to talk more about anything or have any questions
- Remind participants of their right to remove consent and how to do it

C.2.7 Demographic & Technology Survey

Technology in the Lives of Women Living with HIV: Survey

These questions are being asked in order to (1) give an accurate representation of the attendees of this session, and (2) to collect information to be able to compare findings against the findings of other studies involving women living with long-term illnesses.

Completion of this survey is not required in order to participate in the upcoming session, nor is participation in the session required if you complete the following survey.

Once completed, please (1) give to peer-support group leader or (2) retain for the session and return to the peer-support leader or either of the researchers after the session has completed.

Part 1/3 Demographic Information

AGE

Please write your age in the box below:

ETHNICITY

Please write your ethnic origin in the box below:

Part 2/3 Technology Use

Please **circle** all of the following technologies that you regularly use:

- | | | | |
|--|--|---|---|
| Shared Computer
(Home desktop, shared with others) | Shared Laptop
(Home, shared with others) | Personal Computer
(Home desktop, personal use only) | Personal Laptop
(Home, personal use only) |
| Work Computer or Laptop (used at work/public place, e.g. library) | Telephone | Cellphone
(calls/texting only; no data/wifi) | Smartphone
(cellphone that uses wifi and/or data) |

Debit card(s)	Fitness tracker (e.g. fitbit)	Credit card(s)	Wireless Speaker
Metro or bus pass	Watch	Smartwatch (e.g. Apple Watch)	Card/Key fob Pass (automatically opens a door or locker)
Video games (on computer or video game console, e.g. Gameboy)	Radio	Coffeemaker	Microwave
Tablet Device (e.g. iPad)	Flashlight	Alarm Clock	Thermometer
Thermostat (home)	Smart Meter (for home energy use)	Wifi (wireless Internet/data)	Ethernet (Internet via a cable)

heating/cooling

)

Television

Cable/Satellite
Television

DVD or Blu-
ray Player

Library Card

Calculator

(physical)

Camera

(physical, e.g.
DSLR)

Phone

Camera

eReader

(e.g. Kindle)

If you regularly use any technologies **not listed above**, please write them below:

Part 3/3 Website & Application (App) Use

Please **circle** all of the following websites/apps that you regularly use:

Facebook

Twitter

Tumblr

Instagram

Twitch	Pinterest	YouTube	Netflix
Online Shopping (e.g. Amazon, Tesco delivery)	Spotify	Maps/Google Maps	Other online streaming service (e.g. BBC iPlayer)
Email	Texting	Facebook Messenger	WhatsApp
Voicemail	Music played digitally (e.g. iPod or off of a computer)	Digital Calendar (e.g. iCal, Outlook)	Digital Note App (e.g. Notes, Notepad)
Calculator App (on phone or computer)	Game Apps (e.g. Candy Crush, Farmville, Games on Facebook)	Dating App(s) (e.g. Tinder, Bumble)	Online Banking (computer or app)

Google

Facetime/Skype

Internet

Cloud

Browser App

Storage

(e.g. Internet

(e.g.

Explorer

Dropbox,

Chrome,

Google

Safari)

Drive, File

Backup)

If you regularly use any websites/apps **not listed above, please write them below:**

C.3 Analytic Process

Thematic Analysis – Blue Sky Trust

Coding

After transcribing and anonymising the audio recording of the focus group discussion (FGD) I then began my inductive thematic analysis (Braun & Clarke, 2006) process by generating codes using NVivo (see example of NVivo codebook pictured below).

Name	Description	Files	References
fighting for 'us' and fighting for 'BST' being the same; 'nobody will fight for us'		1	2
food being a normal and welcoming aspect of a BST meeting; 'you know that your lunch is settled'		1	1
Giving comparisons as to how BST is opposite to outer discrimination stigma		1	2
having family members help online 'I click on one thing and it appears two things or three [participants agree], I don't understand, how does it happen! I don't like that'		1	1
HIV being secondary issue to other illness or issue		1	1
HIV diagnosis as negative experience; shocking; hard; 'ending my life'; 'is this the end of my life'		1	4
HIV-specific Apps the women use; learning about them through peer community		1	2
How the beautiful physical space of BST positively affects participants		1	1
immigration instability concerns part of neqative life experience		1	1
Individual differences in interest in learning more about using technology; group working together to figure out how to work things		1	5

Initial Themes & Member Checking

I then sorted the codes into initial themes (after reviewing them several times) and wrote a brief summary report to review with stakeholders and participates at Blue Sky Trust. See the text box below for an excerpt of this initial report.

Theme: Identifying Oneself within a Community

Participants continually identified as members within a community structure within peer support. This relates to the core of peer support: relating and/or empathising to others with similar experiences to you. However, there was no central agreed upon terminology for these community structures, but rather three major monikers: a family, fighters, or friends. While elements common to the central community of peer support appear in all three, these terms also define unique views of oneself inside the group within individual journeys. Rather than these terms depicting explicit individual stages of development, they illustrate aspects of one's identity within the group that may include multiple roles.

Subtheme: *Fighters, Strong*

- protection, advocacy, active/applied

P4: We will keep on fighting for it. No one will fight for us, but we fight for each to survive. We do everything. To survive. Because we love Blue Sky.

P4: It's a good place. And we [clears throat] we learn so many things, here. Depression(?), knitting, crochet (some participants laugh gently). Sometimes we knit so many scarves for, for the group, to raise our group to going on because we love it. We don't want to, going to... to go down (noises of agreement). So we are fighting (pause) for it to raise up. That's what we are here for. Because we love it. It's ours. Nobody will fight for us. And we are strong.

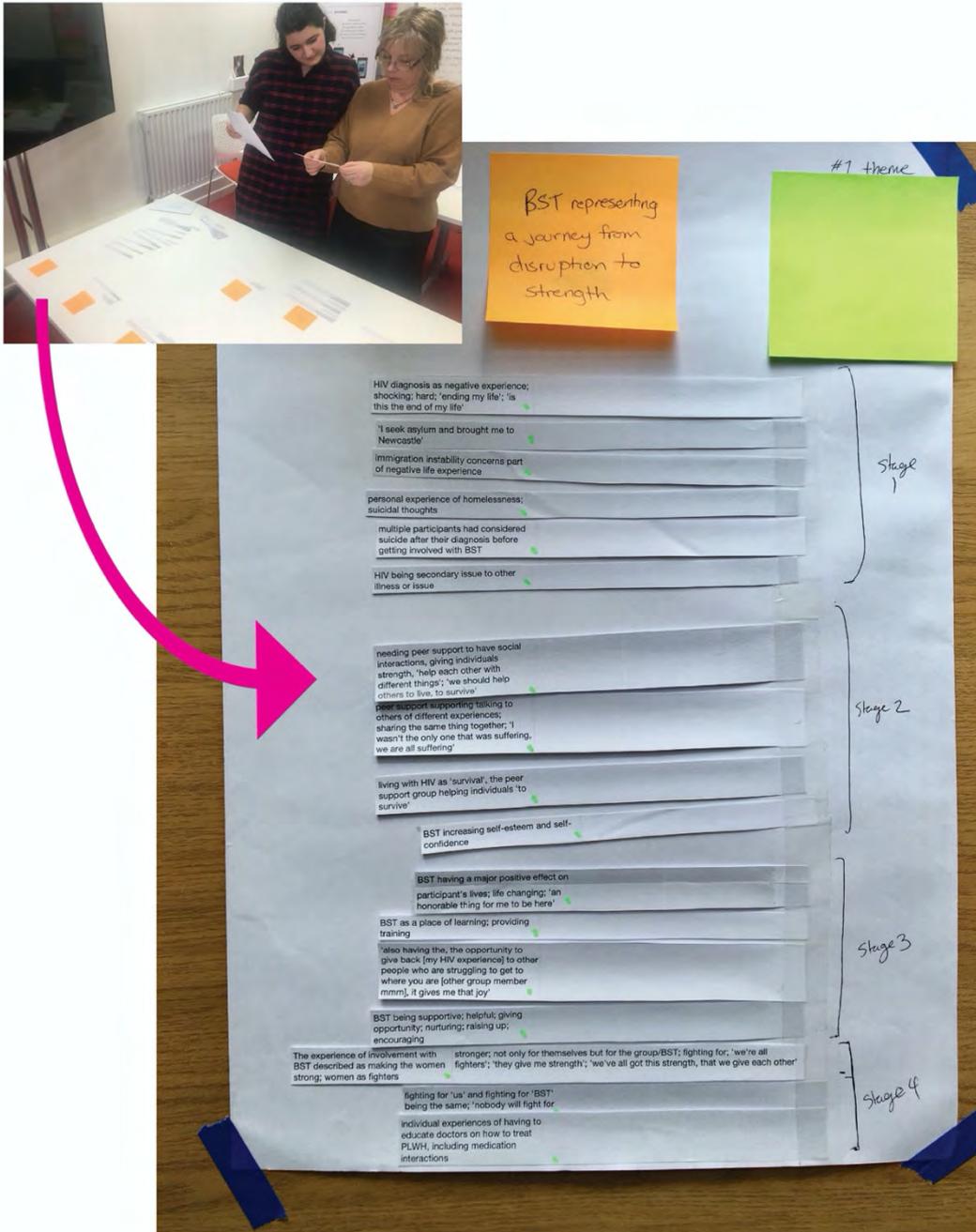
P2: I'm doing PPT... like, explain[ing], talk to the doctors... at the university that want to graduate, explain to them how to treat HIV

patients... because most of them, they're told that if you're HIV... you know because of what the stigma [is, you know what] people are going through, [what] WE are going through.

P7: As I sit in this room with all the women of our group,
Say hi as they come through the door,
Sitting, talking, laughing, crying,
Trying to understand our predicament.
There are no cure for what we have,
But look at us, we are fighting back.
We've grown strong along the way,
Not giving up, not today.
Each day that comes we [hit] it on,
We'll fight it because we have become so strong.
Look how far we have come.

Data Analysis Session #1: Clarifying Themes & Initial Mapping

After the initial themes had been member checked I then reviewed them again with my doctoral supervisors, printing out my NVivo codes and cutting them into strips that could be sorted by hand (see Fig. 3 below). This process helped further refine the themes and began to establish connections between them.



Analysing codes with my doctoral supervisors to clarify themes and establish connections. Image by Author.

D National AIDS Trust (NAT): Reflective Analysis of Internship

D.1 Documentation

Included below is a copy of the contract I drew up with NAT to outline which aspects of my work I could claim as holding ownership over during my internship.

D.1.1 Ownership Contract

National AIDS Trust Work Ownership Outline

Kiersten Hay, Intern: Digital Community Project

Periods of Work: August – December 2018, January—March 2019

VERSION 4.0: 9 January 2019

Purpose of this Document

This document exists to clarify the various items that Kiersten Hay (intern, Community Digital Project) may claim independent ownership of that may fall within the boundaries of intellectual property (IP) ownership of the National AIDS Trust and/or Reason Digital.

This is primarily for the purpose of clarifying and defining independent work from collaborative work and original intellectual contribution, for academic publication and/or academic reporting (such as annual progression reviews of her PhD thesis). This requires the primary author

to retain and be able to prove independent ownership of IP over their published and/or presented content.

Self-Directed Work (may publish independently)

- **All design research activities conducted at the National AIDS Trust that were developed, designed, and/or implemented for the Digital Community Project plus the resulting research materials:**
 - Includes:
 - All forms and research study designs (such as the diamond ranking exercise, the relational information triangle matrix, and circular branding exercises) conducted internally with staff at the National AIDS Trust
 - This include both the original documents (e.g. worksheet design) and any other recording(s) of these activities
 - Also includes development notes, sketches, and activities created by Kiersten Hay in regard to the Community Digital Project
 - Key analytic research findings, such as the need for relationship-based content sorting, useable privacy guidelines (e.g. no online accounts), etc.
 - Also includes any additional design research activities to be conducted during the length of the internship, as agreed upon between Kiersten Hay and NAT

- **Data Review Notes and Analysis**
 - (1) All data analysis and subsequent findings of NAT interviews with stakeholders in connection with the Digital Community Project that pre-exist Kiersten Hay's start date
 - Does not include any raw data, excerpts, or direct quotations from the data (interviews), only the analysis and findings
 - (2) All data analysis of the focus group portions at George House Trust on November 8, 2018 conducted by Kiersten Hay (e.g. not the user studies conducted by Reason Digital)
 - This includes analysis of the audio taken from the event and the collated content lists of the 'top 5' worksheets (not the original filled-in worksheets).
 - Does not include any raw data collected (filled in worksheets), including audio recordings.

- **Focus group structure (NAT-led portions* only) and content**
 - The structure of the NAT-led research portions conducted as half of the focus group at George House Trust with Reason Digital on November 8, 2018
 - *NAT-led research portions within this event includes all activities and discussions led by Kiersten Hay and/or Sean O’Neil. They do not include the user testing activities led by Reason Digital.
 - The content (anonymized transcripts and researcher written notes) of the NAT-led portions of the focus group at George House Trust with Reason Digital on November 8, 2018
 - This data will not be used in its original form in any way. Any audio data will only be retained as anonymised transcripts
 - Full confidentiality will be given to any participant attribution (e.g. names and any other identifying information will be removed from the transcription and/or any excerpts of the transcription)

- **Focus group activity design (NAT-led)**
 - The design of the NAT-led research activities (storyboards, ‘top 5’ lists) conducted as half of the focus group at George House Trust with Reason Digital on November 8, 2018

Collaborative Work (not independent work)

This section outlines items that are considered collaborative and work, and thus cannot be claimed as being independently owned by Kiersten Hay.

- All final digital outputs of the Community Digital Project
 - Such as the website/application itself (code and IP)

- All visual design elements of the Community Digital Project output
 - Includes Community Digital Project branding, illustrations, wireframes and any other final visual product(s) and/or other design assets within the finished application
 - Kiersten may use images of visual elements, such as screenshots, in her thesis and any other research outputs,

provided they are shown/presented with appropriate image credits to NAT and/or Reason Digital

- Wireframes, prototypes, user stories, Reason Digital workshop materials/content, and any other materials/content led by and/or conducted by Reason Digital

Name:

Name:

Position:

Position:

Date:

Date:

Signature:

Signature:

E 4MNetwork: Collaborative Interview Study

E.1 Ethical Approval

Ethical approval was granted for my second empirical research study (4MNetwork: Collaborative Interview Study) by the departmental Ethics Committee at Northumbria University through an amendment to my original ethics application [Ref: 9885] on 10 January 2019. Supporting documentation is provided within the subsequent subsections.

Research Ethics: Amendment Approved

EthicsOnline@Northumbria <EthicsOnline@Northumbria>

Thu 10/01/2019 16:06

To: kiersten.hay <kiersten.hay@northumbria.ac.uk>

Dear kiersten.hay

This email is to notify you that your coordinator (Nick Neave) has approved your amendment request in respect of Research Ethics submission 9885.

Research Ethics Home: [Research Ethics Home](#)

Please do not reply to this email. This is an unmonitored mailbox. If you are a student, queries should be discussed with your Module Tutor/Supervisor. If you are a member of staff please consult your Department Ethics Lead.

E.2 Study Documentation

E.2.1 Recruitment Blurb

This blurb was shared within the 4MNetwork group to recruit participants.

Recruitment Blurb

Hello all. We are carrying out some research and would like to interview 4MNet members about your experiences with the 4M Network WhatsApp group and other mobile apps. Your experiences will help us understand your priorities, and any knowledge, IT or digital skills you want to develop. This will help us design future digital/IT tools (such as websites and apps) and digital/IT training classes to better support you and other women living with HIV in the UK.

The interviews will be held by Kiersten Hay, a PhD student at Northumbria University who is researching how women living with HIV in the UK use technology. She has previously worked with women at Blue Sky Trust, an HIV peer support charity based in Newcastle, and with the National AIDS Trust to help develop their upcoming digital tool for people living with HIV across the UK.

Each interview will take less than an hour, and will be held over Skype or as a regular phone call in February 2019. All interviews will be confidential, with audio recordings of the calls being deleted after the interview has been transcribed (written out) and anonymized. This information will then be used to help us develop an IT training webinar for 4MNet; develop materials for other peer projects; design digital tools; and inform presentation(s) and publication(s) at medical and/or design conferences.

Each participant will receive a £10 Love2Shop voucher for their time. The vouchers will be mailed to each person by Angelina after the interviews have been completed. We are looking for 5-6 participants to interview by February 15, 2019, so please get in touch soon if you are interested!

E.2.2 Consent Statement

This brief was read aloud to participants over telephone/skype at the start of an interview session.

Pre-Interview Brief (done at start of interview session)

Hello. My name is [interviewer's name], and I'm interviewing you today to learn more about how women in the 4MNet group use technology.

As part of this, I would like to record this interview. This recording will be written out in the two weeks following this interview and anonymized, after which the audio recording will be deleted. I will only record this session with your consent.

If you would like to withdraw consent and remove your interview from the research, you can do so at any time during this interview or in the next two weeks, as I will be unable to remove the interview once it has been anonymized. You can do this by contacting me directly at [insert contact details], which I can message to you after this interview, or by getting in touch with Longret. If you choose to withdraw at any time, you will still receive remuneration of a £10 Love2Shop voucher. This voucher will be mailed to you by Angelina after the interviews have been completed.

Please let me know if you prefer not to answer a question or need a break at any point during the interview, so we can pause or skip the question.

Before we begin any recording, I would like to confirm that (1) you give consent to being interviewed, and (2) that you are happy to be recorded.

Do you have any questions before we do a verbal confirmation?

Do you give consent to be interviewed?

Are you happy for this interview to be recorded?

[IF YES TO BOTH] Thank you. Before I start the recording, do you have any questions?

[IF NO TO RECORDING] Thank you. I will only take notes during this interview then. Before we begin, do you have any questions?

[IF NO TO BOTH] Thank you for your time. What we've spoken about so far has not been recorded in any way. Have a good day.

E.2.3 Topic Guide

Interview Questions

Could you please tell me your first name, age, and what region of the UK you are based in?

Do you use the 4MNet WhatsApp group?

What do you mainly use the 4MNet WhatsApp group for? (e.g. asking medical questions, general questions, socializing, finding out about events etc.)?

What is your favourite part about being in the 4MNet WhatsApp Group?

- Has being involved in the 4M Network changed the way you think about yourself?

How would you describe your relationship with the other members of the 4MNet group?

- E.g. as friends, family
- Why?

Is there anything you like about the 4MNet WhatsApp group that you don't think you would get out of an in-person service or in-person peer support group? Why do you like that/those thing/s?

- Do you use any other online platforms (apps, websites) or physical ("real world") services in addition to the 4MNet WhatsApp Group from 4M for support as a mentor mother?

Have you enjoyed using WhatsApp as the platform (app) for this group? Why/why not?

What else do you use WhatsApp for in your daily life?

- Do you use the 4MNet WhatsApp Group in a similar way to other WhatsApp conversations on your phone, or is it different in any way?

Do you use the group for text only, or do you share other media on it (e.g. videos, website links, photos)? What type of content is it (e.g. cute photos of cats, parenting advice blogs)?

- Do you avoid sharing certain types of media/content in the group? Why?

How often do you use the 4M WhatsApp group? (Daily? Weekly?); Why that frequency?

- Do you mainly read messages, post messages yourself, or do both equally?

What do you use your mobile phone for in an average day?

What kind of apps or websites do you use every day? (Social Media: Facebook, Twitter, Instagram, Snapchat; Calendar apps; Google; mobile games; etc.)

Do you use a computer regularly?

- Do you more often use your phone or your computer? Why?

Do you feel confident using technology in your everyday life?

- Why or why not?

Do you have any worries or concerns about using WhatsApp and/or other digital tools for talking about your experiences living with HIV? Why?

- Are there any digital tools and/or platforms (e.g. Facebook, email, a calendar app) that you would be uncomfortable sharing your HIV status on? Why?

Is there anything you wish you knew more about in terms of technology, mobile phones, IT, and/or computers?

Is there anything you wish you could do within the 4MNet WhatsApp group that you don't already? E.g. share calendar events, save webpages, etc.

Are there any digital/IT topics you would like to learn more about through a 4MNet webinar? (e.g. online dating, IT tools, specific programs or apps, etc.)? Anything relating to IT you would like 4MNet to help you with?

Do you have any additional comments or questions?

Extra Time Questions

I'm going to list the other digital tools and platforms 4MNet uses. Please tell me briefly how you enjoy or dislike using that platform, and why, after each.

- Skype (calls and project meetings)
- Email (information dissemination)
- Text messaging (for those without WhatsApp)
- Zoom (webinars)
- Webinars uploaded to Salamander's vimeo webpage
- Surveys on Google Docs
- 4MNet Twitter account

Are there other IT sites you use (e.g. Telegraph, Viber) that you use, which you find easier or more accessible than WhatsApp, that 4MNet might look into?

E.3 Analytic Process

Interpretive Phenomenological Analysis (IPA) – 4MNetwork

Analysis of the 4MNetwork interviews was done collaboratively (between a peer researcher and me) using IPA (Smith et al., 2009).

IPA Overview

Prior to analysis I prepared a brief overview of the IPA analysis method for the peer researcher and I to review during our analyses. The content from this document is provided within the text box below.

Interpretative Phenomenological Analysis (IPA): Overview

IPA is interpretative. As the researcher reads through the written text record (i.e. the transcript) of the interview:

- (i) the researcher tries to relate to what the participant talks about in terms of their experience, and how the participant makes sense of the interviewer's questions; and
- (ii) the researcher tries to make sense of the dialogue between the participant and interviewer (which may or may not also be the researcher), and consider how this dialogue addresses the research questions of the study.

IPA involves a double hermeneutic (the study or interpretation of text):

1. **STAGE 1:** Write your transcripts and listen to the recordings a few times. Once you have done this, go through the transcripts, making codes (notes) in the margins. It's usually easiest to choose one side of the page/document for Stage 1 and the other side for Stage 2, however you can also use different colours if using the same column. Try to write these notes using the words/phrasing the participant's use. These notes should focus on:
 - a. Trying to put yourself in the participant's shoes (empathy);
 - b. Thinking about how they are making sense of the questions you're asking;
 - c. Considering their use of language: What key words, terms, or phrases are used?
 - d. Asking how they are making sense of all these things in the specific context of the interview.

2. **STAGE 2:** Read through the transcripts again, this time writing codes in a different margin. Consider how your research questions are being answered through the answers from participants. These notes should focus on:
 - a. How am I making sense of the answers from participants?
 - b. This is where you analyse/unpack that using your own analysis (e.g. instead of saying ‘they were afraid of their sister choosing for them’, as you might in in Stage 1, you can instead write ‘fear of loss of control in decision making’ in Stage 2).

Stage 1 is about trying to understand and relate to the participant’s thinking/interpretation (in their own words/phrases). Stage 2 is about trying to understand how the interviewer is making sense of the participant in the dialogue between them, and, in turn, how this dialogue addresses the research questions and aims of the study. At this second stage, you can use your own phrasing/terminology on what’s being said. If you like, you can go through the codes/data again after Stage 2, but this is not a requirement.

3. After you’ve completed Stage 1 and 2, you will then group the codes into themes. These themes will represent key aspects of the data.
4. Once there are initial themes, there needs to be some kind of round table review/interrogation of the themes developed. This will be a few people getting together to discuss if there is a clear line between what participants have said to what you’re saying they meant, and if the theme names you’ve decided on make sense or need to be changed.
5. You then solidify your themes, writing out what each one means. Try to use words used by your participants.
6. You then write a narrative account of your data (a report), adding all sections from introduction to conclusion, and including quotations from the interviews to support your themes and subthemes. These sections should take the reader through the process of interpretation, step by step, and include tables that show how the themes developed from Stage 1 (initial codes) to

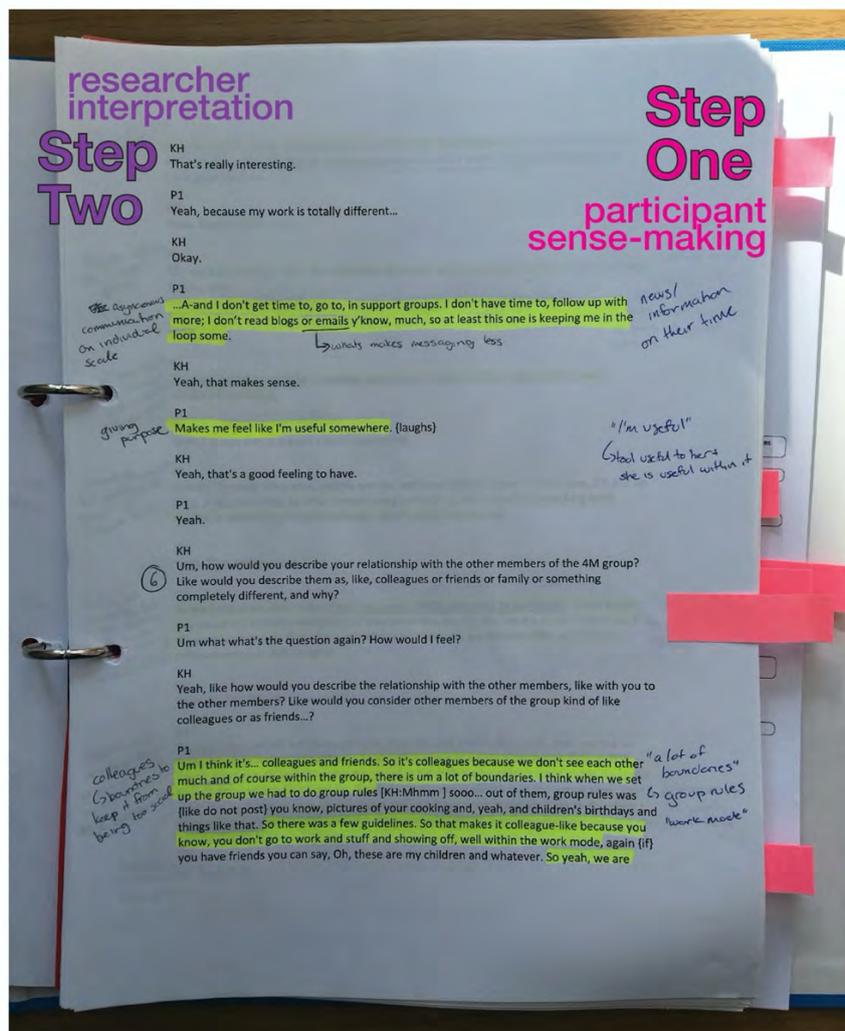
their final grouping and ordering.

7. Lastly, you should include a reflection on your own understanding and processes as a final section (ask yourself “why am I arriving at these findings?”, and relate your own expertise and experience to the findings).

IPA is an approach that focuses on trying to understand the experience of the person being interviewed, and to relate this to your experience, understanding, and aims as a researcher. It is not a fixed method with a ‘right’ or ‘wrong’ way of doing things.

Transcribing Interviews & Manual Coding

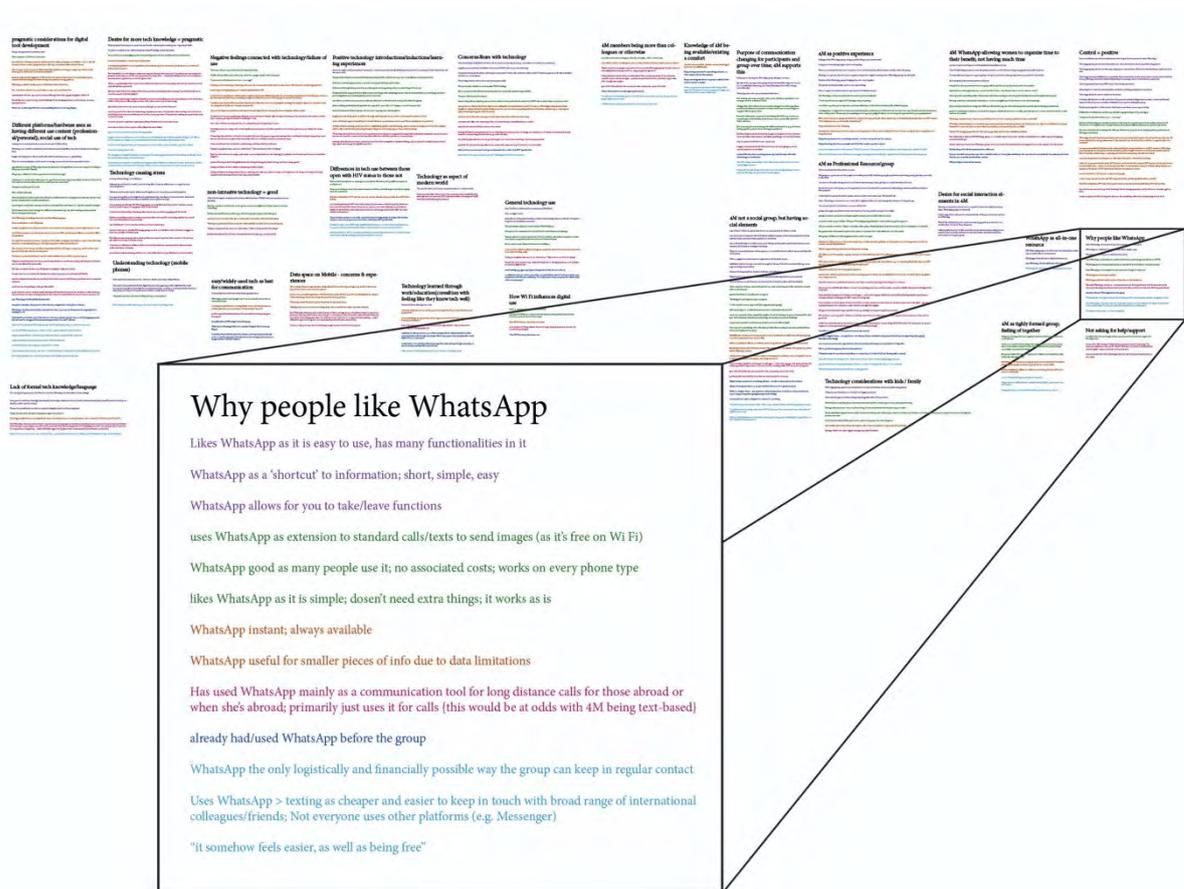
Interviews were manually transcribed and pseudonymised by myself (n=6) and the peer researcher (n=1), sharing our transcriptions with each other via email after completion. I coded the transcripts by hand, using the two-step IPA coding process: first coding how participants made sense of the interview and secondly coding how we as researchers interpreted participants' sense making to address our study's research questions (Smith et al., 2009). An example of this coding is shown below (see Fig. 5). The first stage of codes was done using a blue pen in the right margin. Once complete, I then coded the same transcript for the second stage of codes, using a black pen in the left margin. Coded experts were highlighted.



Manual IPA coding of an interview transcript. Image by Author.

Co-Creating Themes

Our individual codes were then collated and grouped into initial themes through discussions between the peer researcher and me. Sorting was initially done on within an Adobe Illustrator file to allow all themes to be seen on two large pages (see Fig. below). An excerpt of this sorting is provided within the text box following this image below (see below).



Initial themes, laid out on two large pages within Adobe Illustrator.

An excerpt of codes sorted into initial themes.

4M members being more than colleagues or otherwise

sees 4M as more than colleagues, friends, or family – 4M is a bit of each

most 4M members are colleagues, some are friends (knew before); familiar, but not friends

Thinks it may be a stronger connection if she was in the WhatsApp group ("maybe more of a friendship kind of thing would be...happening through that")

Only really hears about others via their shared life or work experience in the webinars; valuable to hear other's thoughts – goes beyond professional data collection to give valuable, thought out insights

part of the Network, but not connected to the community aspect of it really

Views other members as colleagues (professional)

“I really love the friendship circle side of it”/“it just seems like a real sort of sense of sisterhood”
{difference in view}

“I think it's enhanced my admiration for all the women involved”

“I just think the bond is closer than the everyday There is a lot more to it than just you are MM on the project. Does that make sense? There is more to it; we have a lot of connection. There is a lot more connection than just colleagues”

Knowledge of 4M being available/existing a comfort

Comfort of an available, familiar service; knowing it's there and accessible/useful

Enjoys being connected to something national – to other women all over the country

Enjoys knowing that there are people available if she needs to speak to anyone

had a very personal experience with losing a child when HIV medication wasn't developed enough, and wished she had a mentor at that time

Purpose of communication changing for participants and group over time; 4M supports this

Use/purpose of using the WhatsApp group changes over time

the role of the manager of the group allows for individual support to members on individual issues (e.g. not using WhatsApp for a while, will get texted directly)

WhatsApp allows for you to take/leave functions

Use of the group comes and goes with events; if it's been quiet then a new message can have a flurry of action

Change from HIV-related career to not has changed use of the app (from professional information resource to others in the area, to now being less engaged with the group chat)

Personal information a journey in identifying with HIV (e.g. used to use a pseudonym on Facebook); slowly became more comfortable with what info is out there

[about zoom] micro-level changes for different information (e.g. sits down during question period, chores during presentations)

Notified of group updates/events by [PMT1] or [PMT2] via text; Contacted via text when she's asked to contribute something or to attend a webinar

Stays in contact with 4M via text, email, calls

Largely communicated with 4M when there's an event going on, so low contact (considers it monthly)

reviews 4M only when something comes up (event-based); will look when she gets a notification

Uses 4M to keep in touch/up to date with women and post about events/saying happy new year

Non-profit services change and evolve over time through changes in management, funding, and operational structure/goals

"A few times a week, definitely at least once a week, but not daily. Because it's about keeping in touch. It also depends on what we are doing eg if we have a webinar coming up it might be about sending a reminder every week eg. To the run up to the webinar sharing a link every week. It depends on what is happening. Some it can be once a week, once a month but I can't really quantify that because it changes."

Super-ordinate Themes, Internal Study Report, and Final Themes

These initial themes were then analysed using abstraction to form three super-ordinate thematic categories, framed in response to three study research questions (SRQ1-3) co-produced between us.

I then drafted a study report to summarise and present the themes in relation to key participant quotes and our initial themes; this report was reviewed and confirmed as accurate by the peer researcher. We presented the themes and report to collaborative stakeholders at 4MNet and my supervisory team members to further refine and consolidate the super-ordinate themes. This meeting included several documents including: (1) an abstract for the study; (2) a list of our initial themes and codes; (3) an internal report with an overview of the themes; (4) a document providing quotes in relation to the super-ordinate themes/subthemes; (5) a copy of the IPA overview document.

I have included excerpts from documents (3) & (4) below to show how they were reviewed together. The meeting informed our final refinement of the themes, which was done while writing them into a research publication (Hay et al., 2020) and the report presented within my dissertation.

Excerpt from Document (3): Internal Study Report	Excerpt from Document (4): Quotes & Themes
The themes can be structured to address the following three questions:	The themes can be structured to respond to the following three questions:

<p><i>What does the 4M Network use WhatsApp for?</i></p> <p><i>How does WhatsApp work as a platform for Mentor Mothers?</i></p> <p><i>How does the 4M Network WhatsApp group maintain the values of the 4M program?</i></p> <p>1. <u>What does the 4M Network use WhatsApp for?</u></p> <p><i>Response: as a professional community.</i></p> <p>Professional:</p> <ul style="list-style-type: none"> - An information source on HIV news/topics - Focussed, immediate communication with larger group - Work postings, networking, and opportunities - Team management <p>Community:</p> <ul style="list-style-type: none"> - Responsive interpersonal support <ul style="list-style-type: none"> o Posting achievements AND issues - Personal welfare checks - Culture of kindness and empathy 	<p><i>What does the 4M Network use WhatsApp for?</i></p> <p><i>Why does WhatsApp work or not work as a platform for Mentor Mothers?</i></p> <p><i>How does the 4M Network WhatsApp group maintain the values of the 4M program?</i></p> <p>1. <u>What does the 4M Network use WhatsApp for?</u></p> <p><i>Response: as a professional community.</i></p> <p>Participants primarily viewed the 4M Network as a professional community: a professional place for the members of the group to pursue the aims and goals of 4M by supporting each other with information, updating each other on group activities, and sharing personal and group achievements.</p> <p><i>“It's mainly the sharing of information. Asking questions to do with anything... medication or anything that pops up really. I've maybe discussed [something]</i></p>
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	<p><i>with my mentee, and now I wanted to have a point of view from the other mentor mothers, [so] then I will put the question out there. As well, just putting out the information that other members of the 4M [group] can benefit from.”</i></p> <p>[P3]</p> <p><i>“I share information on it about events, training, when we have webinars [or for] making announcements. I also use it to ask for information to inform presentations; If I am doing a presentation and I need perspectives from different women, I use the platform to ask them to give me their input that way. [I also use the platform] to share achievements and photos, so if one of the MM goes and does a talk and I am present I will take pictures and share that. If they appear somewhere and they do something, or win</i></p>
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	<p><i>something, then I share that on the group.” [P7]</i></p>
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F Blue Sky Trust: Zine Workshops

F.1 Ethical Approval

Ethical approval was granted for my third empirical research study (Blue Sky Trust: Zine Workshops) by the departmental Ethics Committee at Northumbria University through an amendment to my original ethics application [Ref: 9885] on 17 October 2019. Supporting documentation is provided within the subsequent subsections.

Research Ethics: Amendment Approved

EthicsOnline@Northumbria <EthicsOnline@Northumbria>

Thu 17/10/2019 10:39

To: kiersten.hay <kiersten.hay@northumbria.ac.uk>

Dear kiersten.hay

This email is to notify you that your coordinator (Nick Neave) has approved your amendment request in respect of Research Ethics submission 9885.

Research Ethics Home: [Research Ethics Home](#)

Please do not reply to this email. This is an unmonitored mailbox. If you are a student, queries should be discussed with your Module Tutor/Supervisor. If you are a member of staff please consult your Department Ethics Lead.

F.2 Study Documentation

F.2.1 Consent Form

Zine Workshops

Blue Sky Trust, October – November 2019

This form outlines that those listed below understand and consent to the following:

- I give permission for the images produced to be published. If published, the images may be anonymised (e.g. faces hidden) to protect individual anonymity, and will be attributed anonymously.
- I consent for group discussions to be audio recorded and transcribed for anonymity.
 - I understand that these recordings will be announced in advance, and that I may remove my consent for my participation in this recording before, during, or up to two weeks after the discussion takes place. Consent can be changed by either speaking with staff at Blue Sky Trust, or directly contacting Kiersten Hay, the lead researcher, at kiersten.hay@northumbria.ac.uk
 - I understand that two weeks after the discussion(s) takes place, an anonymised transcript will be completed and the original audio file will be deleted. At this point I will be unable to remove consent for the inclusion of my input, as it will be anonymous.
- I understand that I will be remunerated with one £10 Love2Shop voucher for my participation in any portion(s) of this workshop series, which will be provided at the end of the study. I understand that this voucher will be given regardless of either (1) my level of participation in the workshop(s); and (2) if I do not give or remove consent for my audio to be recorded in group discussions.

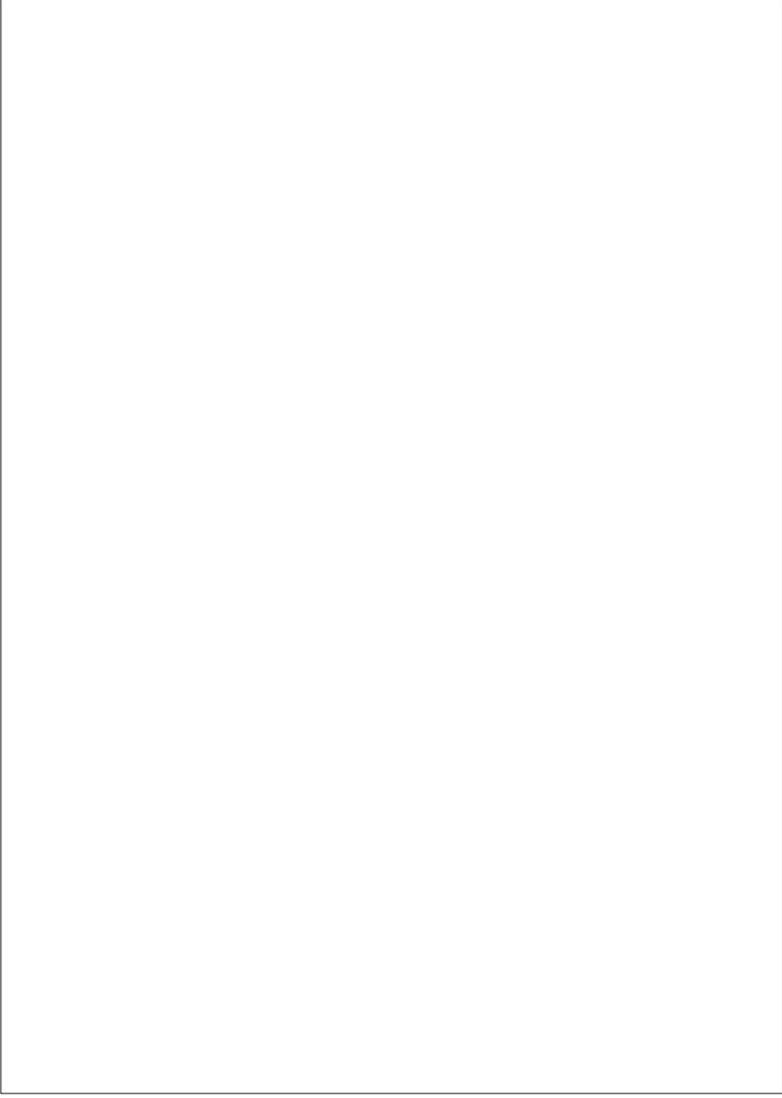
Participants

Name:	Name:
Signature:	Signature:
Date:	Date:

F.2.2 Zine Page (A5) Template

STRENGTH: _____

What does this LOOK like?
What does this SOUND like?
What does this FEEL like?



The form consists of a large outer rectangle with a smaller inner rectangle. The text 'STRENGTH:' is followed by a horizontal line. To the right of this line are three lines of text: 'What does this LOOK like?', 'What does this SOUND like?', and 'What does this FEEL like?'. The inner rectangle is empty and occupies most of the page's vertical space.

F.2.3 Topic Guide

Zine Workshops: Semi-Structured Questions

Blue Sky Trust, October – November 2019

Zine Page Questions [Session 1]

1. Please present your page: what strength(s) does your page focus on and what did you make to communicate that?
2. Why did you choose these (words; design elements; metaphors; etc) for showing this strength to those newly referred to Blue Sky Trust?

Zine Editorial Questions [Session 2]

1. What order do you think these pages should go in? Why?
2. Are there any pages that should not be included? Why?
3. Are there any pages that should be added? Why?
 - a. Is there anything missing from this version?
4. How should the final zine be bound?

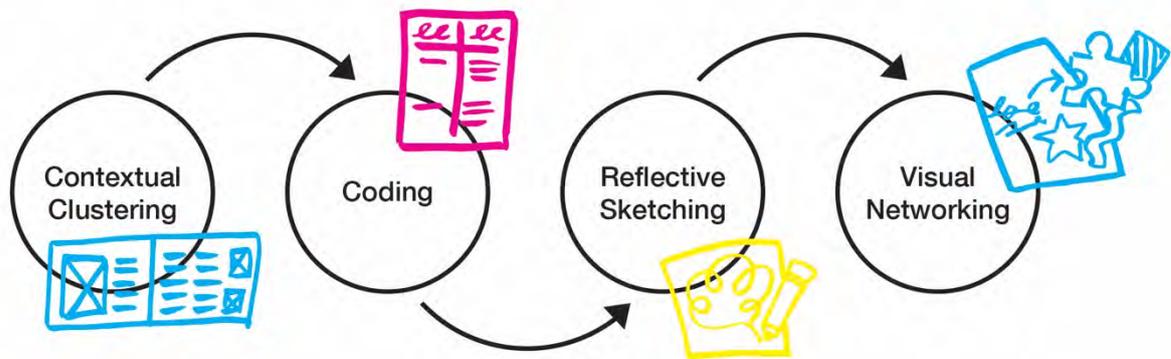
Final Zine Presentation Questions [upon presentation of final zine]

1. What are your thoughts on the final zine?
2. Is there anything you would change (add, remove, adjust)?

F.3 Analytic Process

Zine Analysis – Blue Sky Trust

Analysis of the research process and product of the zine study (Chapter 7) reflects the ‘artful’ and ‘rigorous’ values of this qualitative research approach (Coffey & Atkinson, 1996). This led to choosing to use a novel visual analytic process informed by interpretive phenomenology (Smith et al., 2009) and visual anthropology (Collier, 2004). This analytic process is summarised below, being described in further detail.



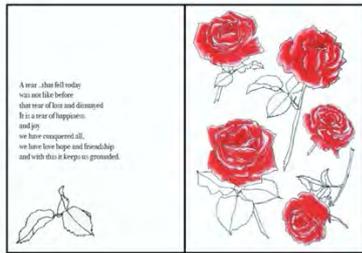
Overview of my visual analytic process. Image by Author.

Contextual Clustering

After transcribing and pseudonymising the audio recording of the zine page presentations and editorial session I began contextually clustering excerpts of the transcript beside images of the zine pages they were describing. The full document is shown (in 2-page spreads) below, while an excerpt from this document can be seen on the following page.



Full layout of all pages used to contextually cluster transcript excerpts beside related zine pages. Image by Author.



Painter: Uhm, the poem, where would that go?

Poet: yeah, where do you want to put the poem?

Maker: those poems, that are written here, in this way, this one here, why do we put that—only, one for the introduction, and then [participants start joining in, agreeing] one, the-the other one, at the end.

Art volunteer: yeah, that's lovely; so what we could do—what would you like to do...

Artist: (speaking over) So, the second one for the first [poem]? And then the other one for the... the end?

Maker: (speaking over): I think the last one, is, is-is only, only... conclusion. At the end, and put... the last—the last one for the last... I don't--this one.

Art volunteer: So 'somewhere along the way I lost myself', so that [poem is] sort of after the introduction...

Poet: so it'll be like there, yeah

Maker: this one [the other poem] will be for the conclusion

Art volunteer: 'a tear that fell today' yeah was... well...

Poet: yeah, can be the last one. Yeah.

Author: what are the—do those [poems] have titles? I'm just writing these down so that we know which is which...

Poet: I didn't give them titles.

Painter: [what are the] titles of that yet...

Author: Oh; what's the start of the one [poem] at the end then?

Art volunteer: Uhm, at the end; (re-citing poem) 'a tear that fell today, was not like before.'

Painter: so a tear that fell today...

Artist: at the end

Art volunteer: that's at the end [Author writing]

Poet: So... that—that, that's... that's a start—there you go.

Art volunteer: I'll write those out.

Art volunteer: 'a tear that fell today' yeah was... well...

Poet: yeah, can be the last one. Yeah.

Author: what are the—do those [poems] have titles? I'm just writing these down so that we know which is which...

Poet: I didn't give them titles.

Painter: [what are the] titles of that yet...

Author: Oh; what's the start of the one [poem] at the end then?

Art volunteer: Uhm, at the end, (re-citing poem) 'a tear that fell today, was not like before.'

Painter: so a tear that fell today...

Artist: at the end

Art volunteer: that's at the end [Author writing]

Poet: So... that—that, that's... that's a start—there you go.

Art volunteer: I'll write those out.

Painter: [seeing Author's drawing] oh, that's a good rose that...

Maker: Oh, it's umm... at the end... we succeed... we've conquered. And the light will come. Because, I said, if (mumbles)... because there was light now. From that light.

Art volunteer: yeah; like sunlight... like a sunrise and then it's...

Art volunteer: Yeah—it's a big size (smiling); and then you wanted the flowers growing...?

Author: beautiful!

Poet: beautiful flower!

Author: glorious!

Painter: beautiful, yeah...

Artist: I like this...

Painter: ...a bright red colour, and vibrant...

Art volunteer: Yes!

Poet: Yeah... it's going to be a big flower.

Art volunteer: (laughs)

Painter: we've come a long way haven't we? Yeah... we've come a long way... it's the journey, we've come a long way isn't it [participants/staff agree]. I know that now, it's a journey... It's all about the journey...

Painter: Umm, the poem, where would that go?

Poet: yeah; where do you want to put the poem?

Maker: those poems, that are written here, in this way, this one here, why do we put that—only, one for the introduction, and then [participants start joining in, agreeing] one, the-the other one, at the end.

Art volunteer: yeah, that's lovely; so what we could do—what would you like to do...

Artist: (speaking over) So, the second one for the first [poem]? And then the other one for the... the end?

Maker: (speaking over): I think the last one, is, is-is only, only... conclusion. At the end, and put... the last—the last one for the last... I don't--this one.

Art volunteer: So 'somewhere along the way I lost myself', so that [poem is] sort of after the introduction...

Poet: so it'll be like there, yeah

Maker: this one [the other poem] will be for the conclusion

Art volunteer: 'a tear that fell today' yeah was... well...

Poet: yeah, can be the last one. Yeah.

Author: what are the—do those [poems] have titles? I'm just writing these down so that we know which is which...

Poet: I didn't give them titles.

Painter: [what are the] titles of that yet...

Author: Oh; what's the start of the one [poem] at the end then?

Art volunteer: Uhm, at the end; (re-citing poem) 'a tear that fell today, was not like before.'

Painter: so a tear that fell today...

Artist: at the end

Art volunteer: that's at the end [Author writing]

Poet: So... that—that, that's... that's a start—there you go.

Art volunteer: I'll write those out.

Painter: [seeing Author's drawing] oh, that's a good rose that...

Maker: Oh, it's umm... at the end... we succeed... we've conquered. And the light will come. Because, I said, if (mumbles)... because there was light now. From that light.

Art volunteer: yeah; like sunlight... like a sunrise and then it's...

Art volunteer: Yeah—it's a big size (smiling); and then you wanted the flowers growing...?

Author: beautiful!

Poet: beautiful flower!

Author: glorious!

Painter: beautiful, yeah...

Artist: I like this...

Painter: ...a bright red colour, and vibrant...

Art volunteer: Yes!

Poet: Yeah... it's going to be a big flower.

Art volunteer: (laughs)

Painter: we've come a long way haven't we? Yeah... we've come a long way... it's the journey, we've come a long way isn't it [participants/staff agree]. I know that now, it's a journey... It's all about the journey...

An excerpt from the contextual cluster pages. Image by Author.

Coding

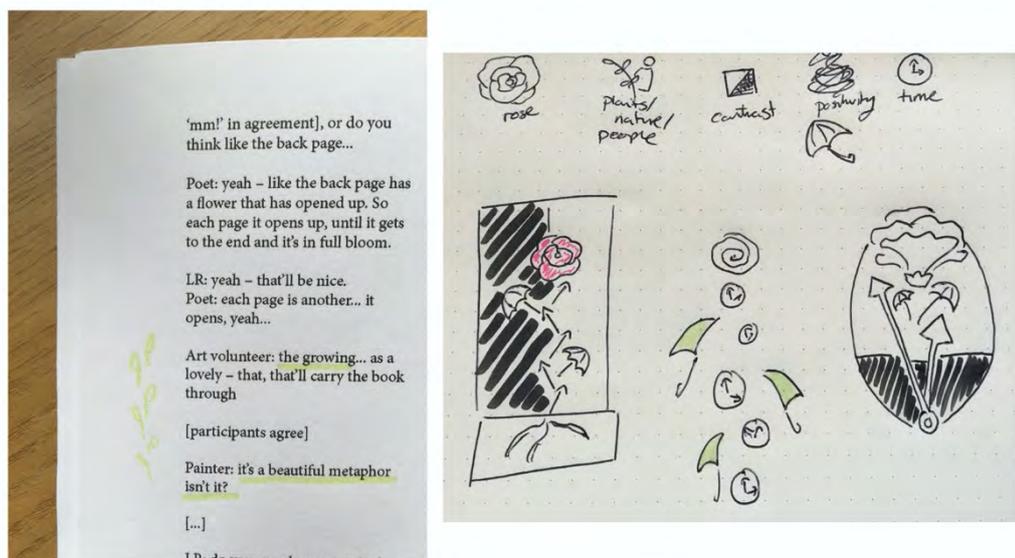
I first attempted to code the contextual clusters using annotations, however this fail due to the entwinement of similar metaphors and narratives throughout the clusters. I instead read through the contextual cluster document several times, creating a list of voiced experiences that had distinct visual representations within the zine (see Table below).

Taxonomy of distinct experiences and their visual representations within the zine.

Experience	Description	Representation
“It starts off rough and ends up beautiful”: The blooming rose as personal growth	The peer support journey as an unfolding process of positive personal growth	Visual metaphor of a red rose blooming
“Do not fear change, change fear”: Reframing moving forward	The importance of acceptance and resilience in starting and moving forward within the peer support journey	Images of nature and people juxtaposed with positive sentiments and phrases describing a hopeful and resilient progression through life
“All I could see was black all the time, and that’s what I felt”: Expressing negative experiences	Focusing on the change from negative to positive experiences rather than explicating negative events	Contrasting pairs of poetry and abstract artwork to shown change from negative to positive
“Opening up... starting to lift”: Growth through positive experiences	The value of receiving and providing forms of care (e.g., love, joy) within the peer support journey	Direct representation of positive experiences or values (e.g. food as food)
“All about patience and time”: clock faces and the importance of temporality	The importance and value of peer support as a temporal space for healing and growth	Visual metaphor of a clock face

Reflective Sketching

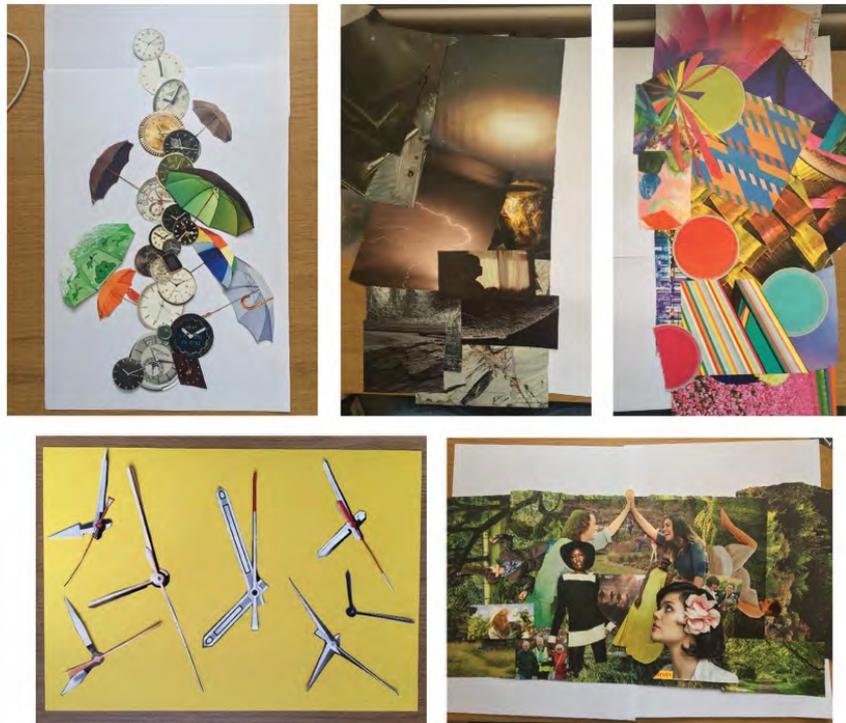
Reflecting on this taxonomy, I considered how these experiences (as voiced and visualised through this zine-making study) related to each other as an interconnected process (or network) rather than a hierarchy of distinct themes. I previously had found sketching easier than annotating with words while reviewing the contextual clusters, as shown in the Figure below (left image) below. Distinct experiences harmonised with each other in relation to each woman's subjective journey and visuals at different points, highlighting the importance of presenting them in connection with each other and the plurality of these connections for each participant. Inspired by the visual narrative representations of research outcomes presented in research work led by women living with HIV (e.g., ICW, 2004; Orza et al., 2014), I then began sketching a visual representation of this network, using the visual language of the illuminated experiences to depict their entwinement (Fig. below, right image). This approach allowed for distinct experiences to be represented as individual elements with abstract interconnections, reflecting my sensemaking of the data.



Sketches within the contextual clustering booklet (left image); sketching out the connections between icons of taxonomy figures (right image). Image by Author.

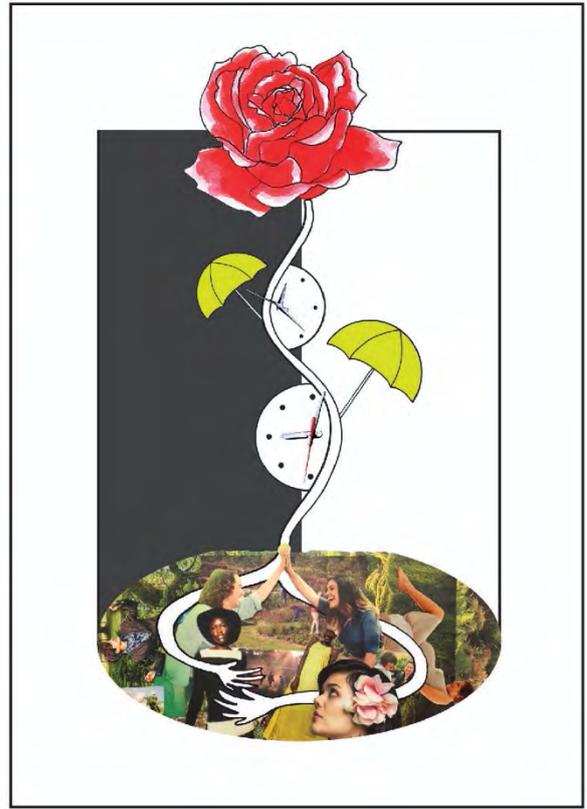
Visual Networking

I chose to illustrate this visualised network of experiences using same materials as the zine artefact (collaged magazine images, illustrated roses) to reflect its material language. Guided by the taxonomy, I collected (using the magazines that had been used for the original workshop sessions) and collaged various images to reflect the identified experiences (see Fig. below).



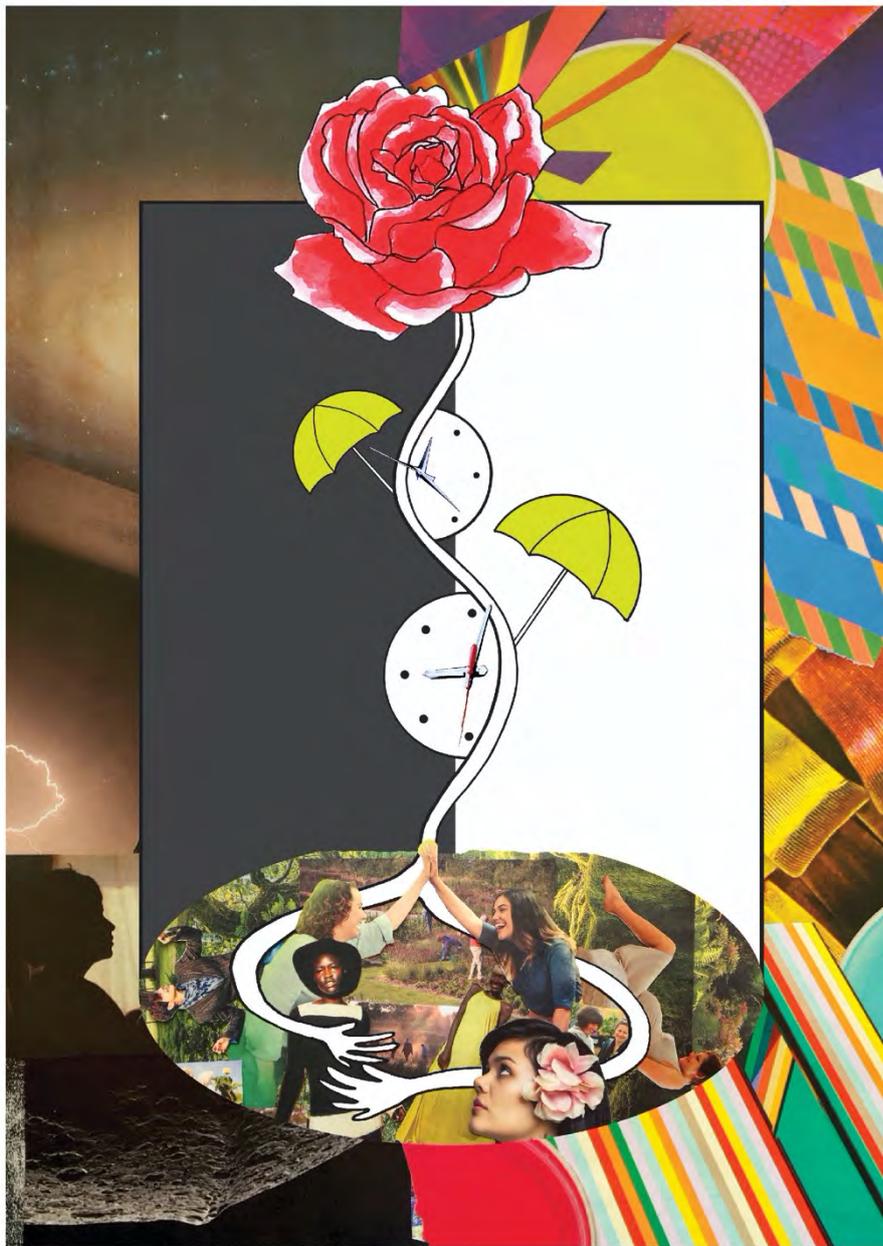
Collages made using found magazine images. Images by Author.

These collages were scanned and further collaged digitally (next Figure). Iterating within these drafts, I refined my collage and added additional sketched visuals (clock faces, hands as roots) to improve clarity between the distinct visual representations.

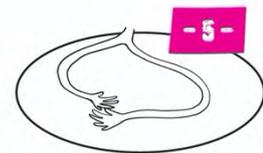
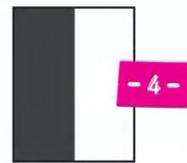
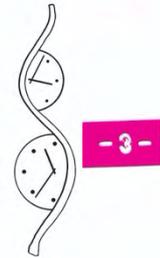


Drafted version of digital collages using magazine images (left) and sketched assets (right). Images by Author.

I added a legend with icons of the individual elements within the final visual network (next page) to further clarify it as a thematic map of individual elements. I then used this legend to inform my final report, as included within my dissertation.



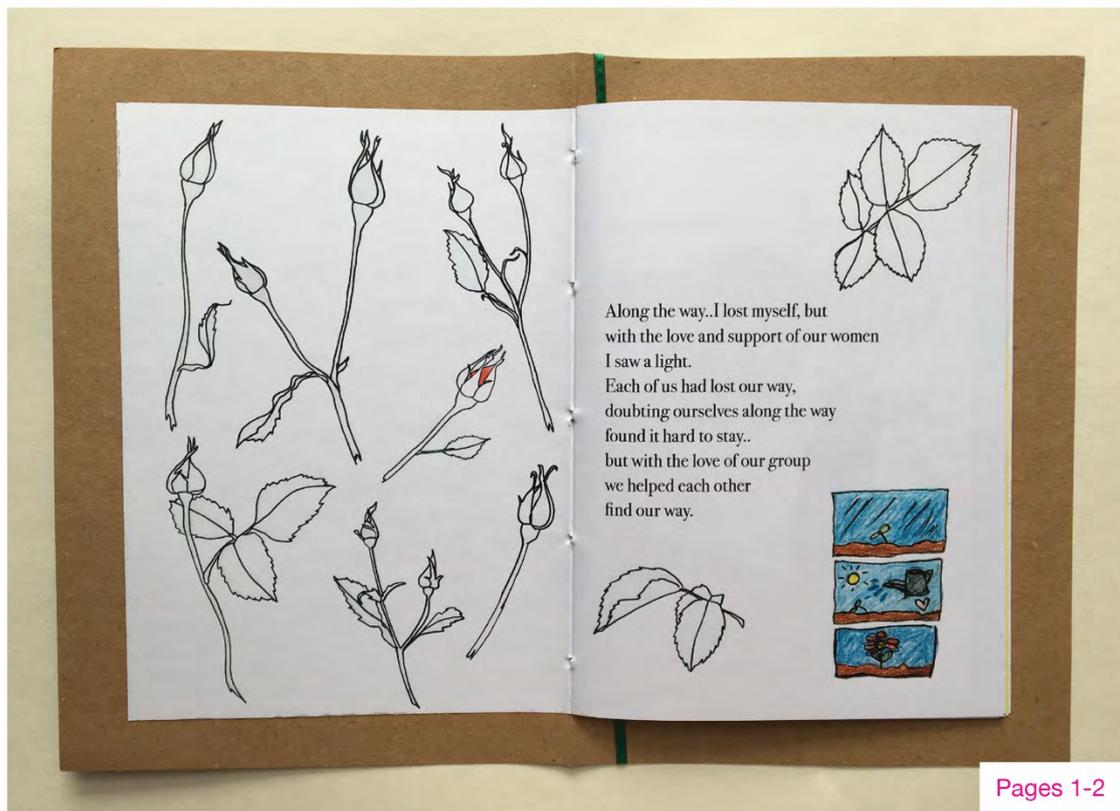
LEGEND

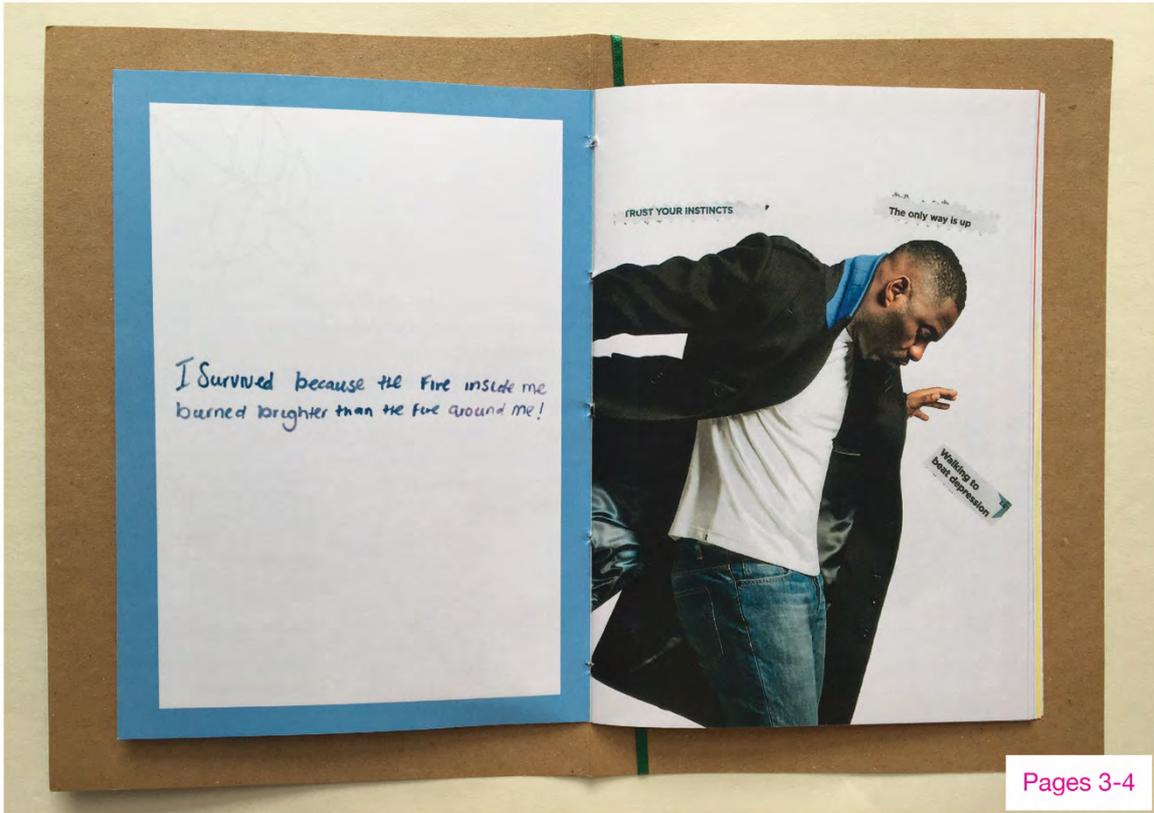


Final networked collage, with legend of specific visual components on the right side.

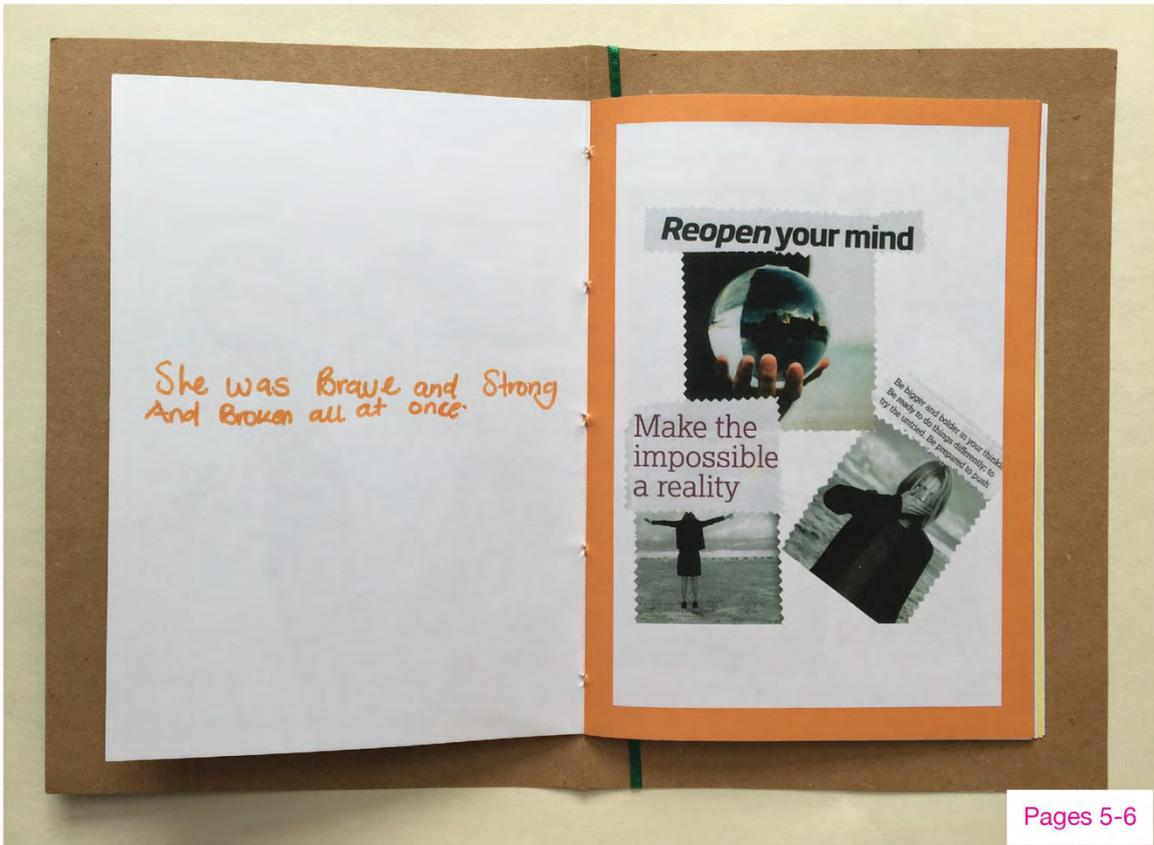
Photo by Author.

F.4 Final Zine





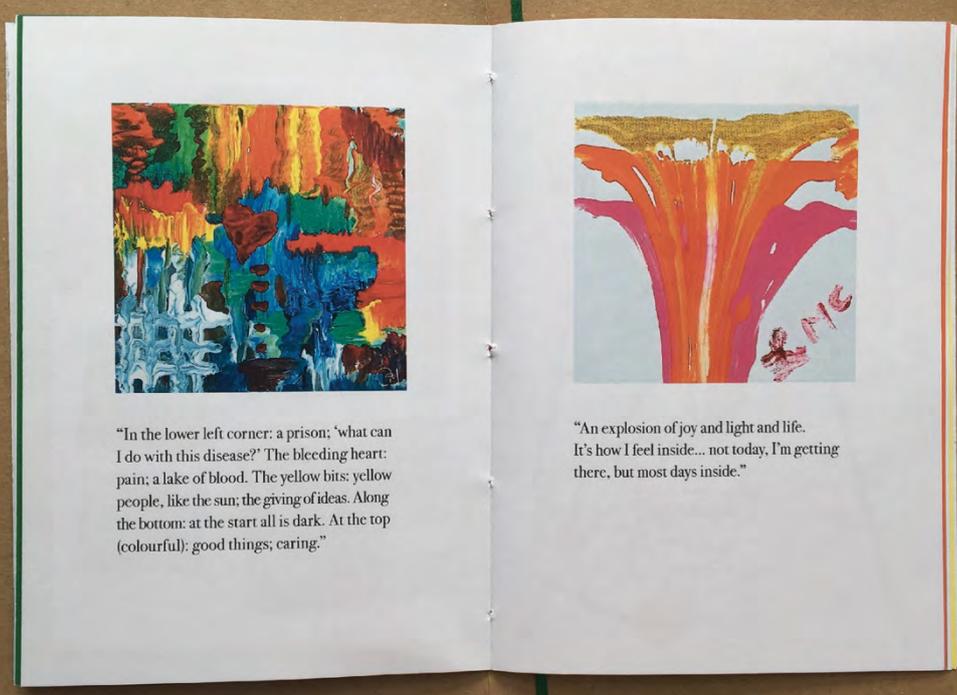
Pages 3-4



Pages 5-6



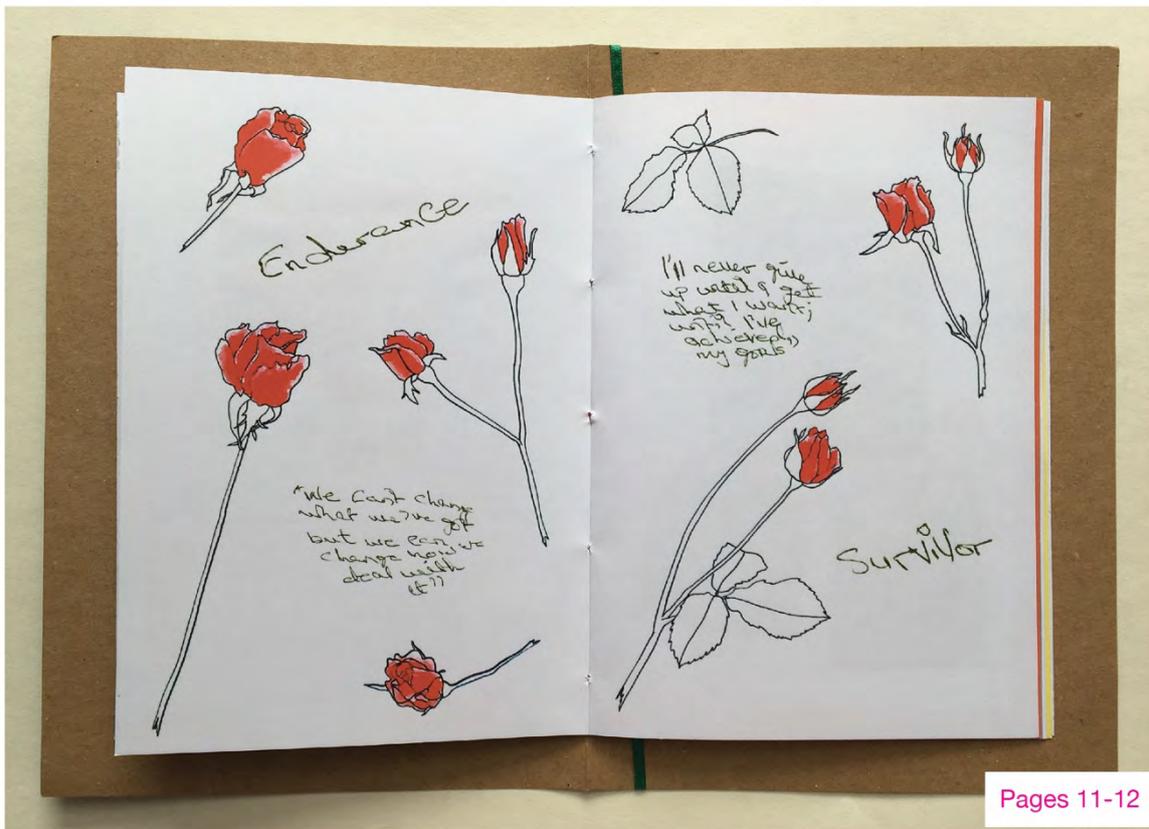
Pages 7-8



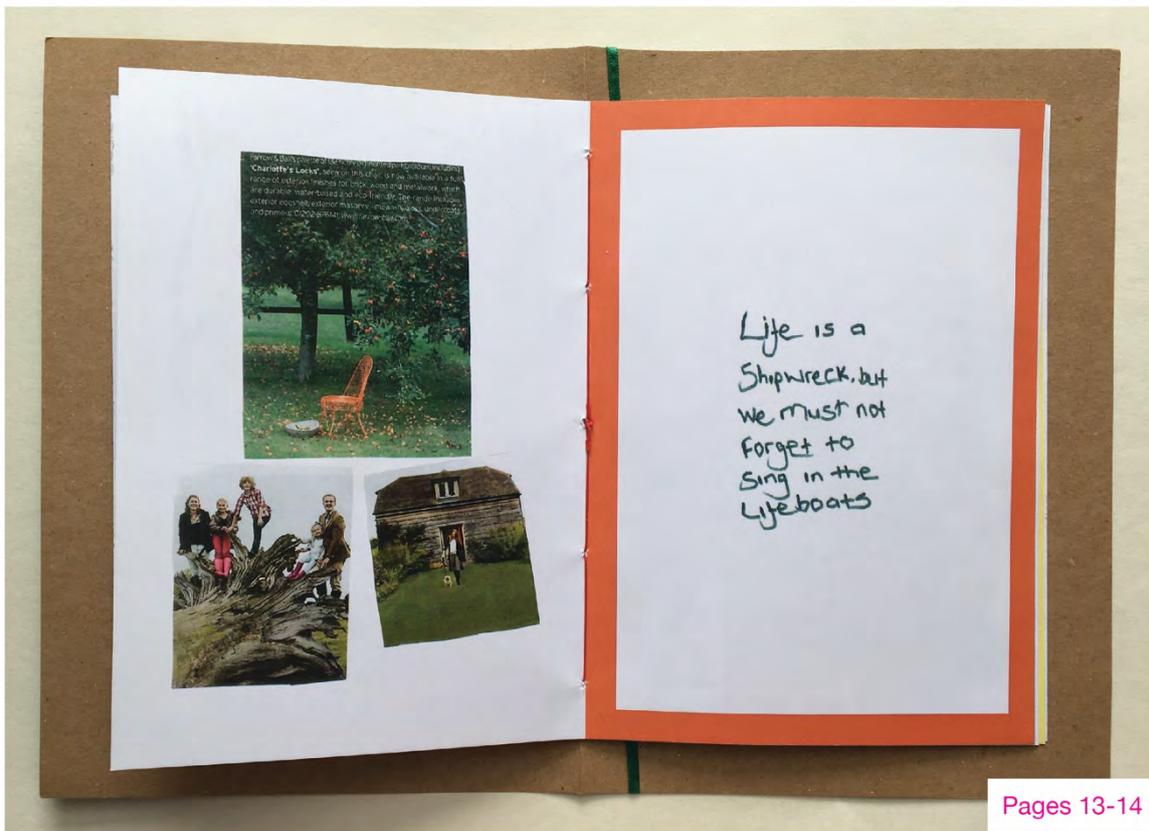
"In the lower left corner: a prison; 'what can I do with this disease?' The bleeding heart: pain; a lake of blood. The yellow bits: yellow people, like the sun; the giving of ideas. Along the bottom: at the start all is dark. At the top (colourful): good things; caring."

"An explosion of joy and light and life. It's how I feel inside... not today, I'm getting there, but most days inside."

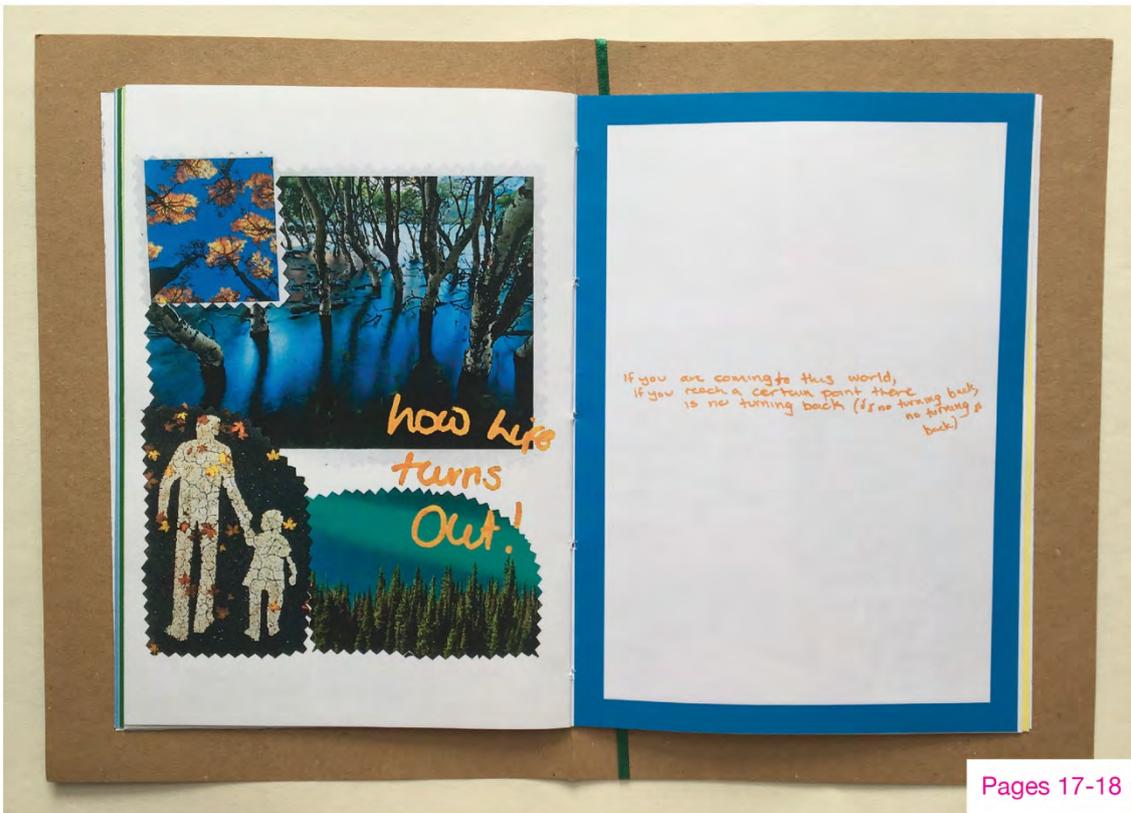
Pages 9-10



Pages 11-12



Pages 13-14



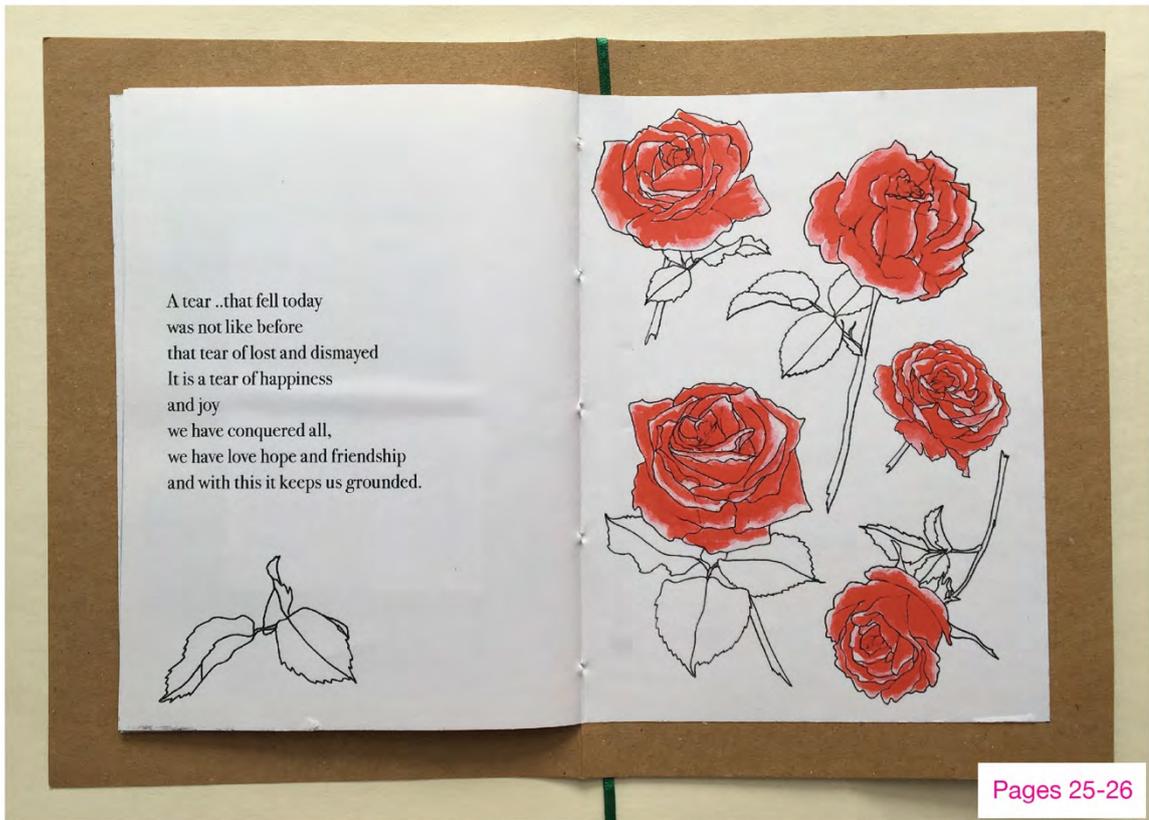


Pages 19-20



Pages 21-22





Pages 25-26



Back Cover



Full Cover

11 Glossary

This doctoral work sits within an interdisciplinary space, drawing upon language from a number of specialist discourses. Definitions of key terms are included below for clarity.

Agonism

Agonism is a political perspective that emphasises the “affective aspects of political relations,” viewing disagreement and confrontation as positive and ongoing aspects of political dialogue (DiSalvo, 2015, p. 5). Agonism was introduced to HCI Design discourse through Carl DiSalvo’s *Adversarial Design* (2015), an approach to design practice that uses the means and forms of Design to challenge beliefs, values, conventional approaches to political issues. In this way *Adversarial Design* involves the political, not Politics.

Antiretroviral therapy (ART)

Antiretroviral therapy (ART) is the current medical treatment for HIV, and involves taking three different drugs at the same time, often combined in one tablet (Terrence Higgins Trust, 2021). Continual use of ART lowers the level of HIV within a patient’s blood (or viral load), with ongoing effective use lowering the viral load to undetectable levels (see U=U).

Communication Design

Communication Design is a broad sub-discipline of Design that focuses on designing communicative artefacts (Forlizzi & Lebbon, 2002), or how aspects of the interaction between a source, message, and viewer may be designed to communicate specific meanings. Communication Design incorporates expertise from a range of

Design specialisms, including but not limited to: Graphic Design, Advertising, Illustration, Animation, Typography, Web Design, Interaction Design, and Art Direction.

Community-based approaches

Community-based research approaches guide a range of methods that involve equitable partnerships between academic and community organisations or entities “with the goal of increasing the value of the research product for all partners” (Coughlin et al., 2017, p. ix). Community-based *Participatory* Research (CBPR) and Design (CBPD) approaches are related to other social justice-informed methodologies, such as Participatory Design (PD) and Participatory Action Research (PAR), in seeking to work with communities to identify issues and respond appropriately. Community-based participatory approaches consider the strengths and insights of all collaborating partners and seek to establish true partnerships to leverage these effectively. Within Participatory Design discourse, Community-based Participatory Design (CBPD) is a developing field that “highlights the social constructs and relations of groups in settings that include, but go well beyond, the formal organisational structures commonly foregrounded in more traditional workplace studies” (DiSalvo et al., 2012, p. 182).

Co-Creation

In this dissertation, I use Co-Creation to refer to the collaborative making of something involving two or more people. As informed by the definition by Design scholars Elizabeth Sanders and Pieter Jan Stappers, Co-Creation is “a very broad term with applications ranging from the physical to the metaphysical and from the material to the spiritual, as can be seen by the output of search engines” (Sanders & Stappers, 2008, p. 6).

Co-Design

Co-Design is the design practice of Co-Creation, wherein collaborative activity is used within Design processes. As this doctoral project uses Community-based approaches, I refer to Co-Design as informed by Design scholars Elizabeth Sanders and Pieter Jan Stappers' definition, meaning "to refer to the creativity of designers and people not trained in design working together in the design development process" (Sanders & Stappers, 2008, p. 6).

Critical Phenomenology

Critical Phenomenology is a contemporary approach to Phenomenology's study of lived experience and meaning making, informed by Post-structuralism and Critical Theory. Critical Phenomenology seeks to understand the everyday experiences of others with acknowledgement of how *ways of seeing* and *making the world* are coloured by historical and social structures of power (Guenther, 2020).

Digital Health

I refer to Digital Health as defined by the World Health Organisation (WHO), to mean "The field of knowledge and practice associated with the development and use of digital technologies to improve health" (World Health Organization, 2021, p. 39). This term encompasses eHealth and mHealth (described below), expanding these concepts in include digital consumers and any digital technology (ibid.).

eHealth

The use of Information and Communication Technologies (ICTs) in supporting Health and Health-related fields (World Health Organization, 2021). The term 'eHealth' is commonly used within Health-related discourses. See also Digital Health and mHealth.

Emancipatory HCI

Emancipatory HCI is a sub-genre of Humanist HCI, defined by HCI academics Jeffrey Bardzell and Shaowen Bardzell "any HCI research or practice oriented toward exposing and eradicating one or more forms of bondage and oppression, including structural racism, poverty, sexual repression, colonialism, and other forces/effects of the hegemonic status quo" (J. Bardzell & Bardzell, 2015, p. 115).

Entanglement HCI

HCI academic Christopher Frauenberger proposes Entanglement HCI as a conceptual approach to a developing Fourth Wave HCI research paradigm, in which "humans and their things are ontologically inseparable from the start" (Frauenberger, 2019, p. 21). In this view, the intimate interdependencies within socio-material arrangements of humans and things are acknowledged, making "any attempt to study humans or technology in separation... necessarily flawed" (Frauenberger, 2019, p. 3).

Expert Designer(s)

Within this dissertation I refer to expert designer(s) in relation to Ezio Manzini's (2015) definition and distinction of 'expert design,' to mean someone trained and experienced in ways of doing design as an evolved skill or discipline rather than the broad human ability to design (which Manzini refers to as 'diffuse design'). In this way 'expert' designers refers to those "specially equipped with conceptual

and operational tools to support designing processes” (Manzini, 2015, p.38).

I use the terminology of ‘expert designer(s)’ within this dissertation to focus on how collaborating with others may impact one’s design praxes, or how a designer’s specialist expertise of their design practice(s) or material(s) may be affected when working with others, rather than to argue who may qualify as a ‘designer’. As a communication designer, I refer to myself as an ‘expert designer’ in relation to my specific expertise in understanding how beliefs may be communicated through designed artefacts to a given audience in order to promote a desired effect (e.g., instilling new beliefs). As this dissertation is positioned within an interdisciplinary space, this phrasing was also chosen to underscore the importance of design practitioner expertise within design-led research. As a communication designer, this aspect of design research felt important to highlight given that research seeking to understand audience beliefs (in order to design appropriate artefacts) may be misunderstood as not being design-led research when not immediately linked to, or resulting in, a designed artefact.

Healthcare

Within this dissertation I refer to healthcare to mean health services provided by trained and licensed professionals, such as clinical health services, “related to the treatment, control, management or prevention of a disease, illness, injury or disability, and the care or aftercare of a person with these needs” (Department of Health and Social Care, 2018, p. 17).

Interaction Design (IXD)

Interaction Design (IXD) is a sub-discipline of Design that focuses on designing interactive artefacts, including digital and non-digital systems and services that respond to people's interaction with them (Sharp et al., 2019). The interdisciplinary field of Human-Computer Interaction (HCI) is a key domain of interest for IxD practice.

ICTs

Information Communication Technologies (ICTs) refer to all digital communication technologies (such as the Internet, cell phones, wireless networks, video conferencing, social networking) that allow users to access, transmit, or otherwise interact within information digitally.

mHealth

mHealth, stands for mobile health, and refers to Digital Health interventions that use mobile devices (such as smartphones or tablet computers) for the delivery of healthcare services (Sowon & Chigona, 2020). The term 'mHealth' is commonly used to refer to healthcare services delivered through smartphone applications (or apps). See also Digital Health and mHealth.

Praxis

Praxis refers to the relationship between thinking and doing: "in its simplest form, praxis can be considered to be a way of thinking about action and a way of acting on thought" (Crouch & Pearce, 2019, p. 40). The historical roots of Praxis are in Aristotle's division of human activity into three parts: *theoria* (contemplation), *poiesis* (activities of production), and *praxis* (the way in which we do things) (ibid.). Within Design discourses, Praxis is considered in relation to how designers consciously move between thinking and doing within their design practice, whereby practices may change and be changed throughout

the design process (ibid., p. 42). I refer to ‘design praxis’ to reflect the designer’s agency in this unfolding aspect of design practice, wherein the body of knowledge informing design practices is always in flux.

Socio-materiality

Socio-materiality refers to the entanglement of the material world (i.e. things, objects, artefacts) and the social world of humans. In this dissertation I refer to socio-materiality through a Communication Design lens (Tyler, 2006), looking specifically at how the designed, tangible form of artefacts may actively communicate meaning themselves (Clarke et al., 2021).

Social Support

I refer to social support within the context of HIV to describe emotional (e.g., providing empathy), instrumental (e.g., providing transport), and informational (e.g., advice) forms of supportive care (Cohen et al., 2000; Huh et al., 2014). social support may be provided informally (e.g., by family and friends) or formally (e.g., through social support Service provision).

Social Support Services

I refer to social support services within the context of HIV to include “any service provided to meet HIV-related needs of people living with HIV, other than those provided as part of primary or secondary clinical care” (The National AIDS Trust, 2017, p. 13). Within the UK, HIV social support services are predominantly provided by the HIV voluntary and community sector, and include a range of services not limited to advice or information services, self-management education, and peer support. I refer to these services as ‘social support services’ to demarcate them from clinical healthcare services and reflect how

their rich variance is united through consideration of the social impact of HIV on daily life.

Social Care

Social care is not social support (described above), but instead refers to supportive services “providing help, care and protection from harm for adults with physical disabilities, learning disabilities, or physical and mental illnesses... this can include help with washing, dressing, getting out of bed in the morning, help taking medicine, and help with the housework” (The King’s Fund, 2017). I have included this term to distinguish social care from social support.

Undetectable = Untransmittable (U=U)

Advances in medical treatment (see ART) mean that HIV can be managed as a long-term health condition (LTC). Maintaining adherence to HIV medication results in an undetectable viral load, making it impossible for the virus to pass on to anyone else, also known as Undetectable Equals Untransmittable or U=U (Rodger et al., 2016).

Woman Living with HIV

Any person living with HIV who identifies themselves as a woman. I refer to women living with HIV without using abbreviations or acronyms (such as WLWH) in this dissertation to use ‘people first language’ (Pullin, 2009, p. 2), framing individuals as people with secondary consideration for relevant pathology.

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