

“I was not meant to be here, and I’m
still here”: a feminist, participatory
and assets-based exploration of
women’s experiences of ageing with
HIV in London

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requirements of the University of Greenwich for
the Degree of Doctor of Philosophy

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DECLARATION

"I certify that the work contained in this thesis, or any part of it, has not been accepted in substance for any previous degree awarded to me, and is not concurrently being submitted for any degree other than that of Doctor of Philosophy being studied at the University of Greenwich. I also declare that this work is the result of my own investigations, except where otherwise identified by references and that the contents are not the outcome of any form of research misconduct."

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My wonderful son, Arlo, was born 26 hours after I passed my Viva. Arlo, thank you for waiting just long enough to let me finish. This is for you.

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ABSTRACT

This research adopts a feminist and assets-based approach to explore the experiences of women ageing with HIV in London. Building on the foundation of a systematically approached review of the social science literature on ageing, women and HIV, it identifies key gaps in the evidence base and limitations in the epistemic conditions of its production. A comprehensive review of conceptual and theoretical literature on the concepts of participation and community follows, from which emerges a theoretical framework and research praxis that uses feminist and reflexive approaches to define a model of 'research as advocacy'. This model seeks to use narrative and story-telling to both understand women's experiences of ageing with HIV, and to expand the evidence base through original methodologies and approaches. Innovative methods used include participatory creative workshops (including a body mapping exercise), participatory literature review, life story interviews and a participatory analysis. These methods, supplemented also by a policy review and stakeholder interviews, generate new evidence on the experiences of women ageing with HIV in London. Three themes emerge from this research: persistence; participation and personal connections; and resilience. Living long-term with HIV for many women includes the experience of surviving a terminal diagnosis, which brings with it emotional and psychological challenges encapsulated in the concept of 'survivor conflict', developed and presented in this study. The experience of living with HIV enables participation in an HIV community and shapes relationships and belonging within wider communities and social networks. This thesis therefore offers both methodological exploration and innovation as well as findings on the health and social care needs and experiences of older women living with HIV.

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1. INTRODUCTION

1.1 HIV and ageing in the UK

Ageing with HIV is a relatively new phenomenon. People diagnosed with HIV in the 1980s and early 1990s were given a terminal diagnosis. They did not expect to survive, much less reach older age. When effective antiretroviral treatment became available in the mid-1990s, HIV became treatable, dramatically altering the experience and prognosis of people living with it (UNAIDS 2013). People living with HIV and accessing treatment can now expect a normal life expectancy (May, Gompels et al. 2014). Many people diagnosed in the early period of the pandemic can now expect to live to an old age. Additionally, increasing numbers of older people (aged over 50) are being newly diagnosed with HIV (UNAIDS 2013).

Women are a minority among people living with HIV in the UK, and older women a minority again, so their specific experiences can be overlooked (Sophia Forum and Terrence Higgins Trust 2018). Ageing with a chronic condition is difficult, as growing older can reduce ability to self-manage health and amplify the impact of the condition and associated vulnerabilities (Giddings, Roy et al. 2007, Hewitt-Taylor, Bond et al. 2013). Ageing with a stigmatised condition like HIV is perhaps more challenging still. This thesis explores how women adapt, cope and support themselves, and each other, to age well with HIV.

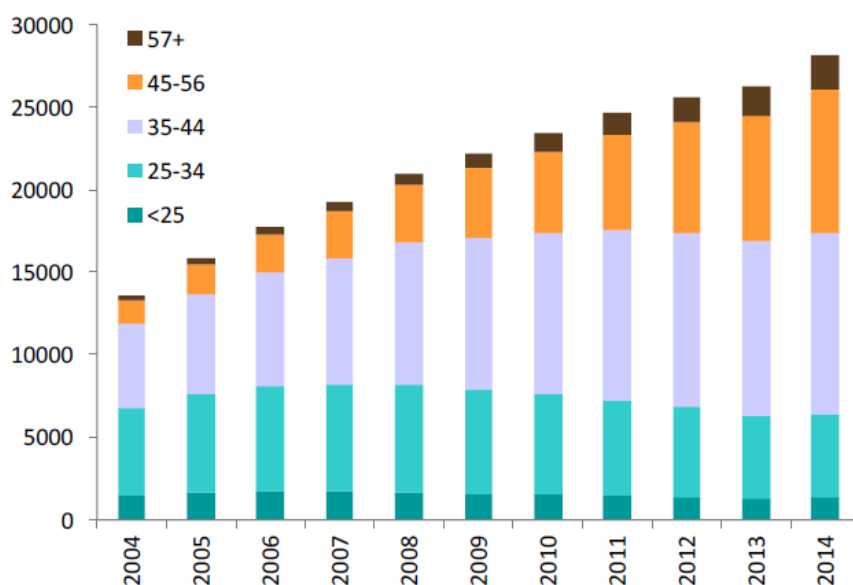
Ageing with HIV is ever more important to understand, in terms of personal, health and social care challenges and strategies to address them (Power, Bell et al. 2010, UNAIDS 2013, Rosenfeld, Anderson et al. 2015). Yet it is an issue that is only recently gaining the attention of researchers. There are many questions and unknowns. The experiences and needs of older people living with HIV are multiple and varied: social care needs related to HIV and other conditions; age-related care needs; health needs linked to HIV or ageing; and co-morbidities; (Power, Bell et al. 2010, Rosenfeld, Anderson et al. 2015). These are further complicated by social and economic factors linked to stigma, deprivation and isolation. Further, people living with HIV may face additional, intersectional challenges linked to gender, sexuality and race, in the context of a socially stigmatised condition.

Women represent a large minority (29%) of people living with HIV in the UK (Public Health England 2018). The population of people living with HIV in the UK is ageing, with 39% of people receiving HIV care in 2017 aged over 50 (Public Health England 2018). New diagnoses are increasing for older people, with 20% of new diagnoses in people aged over 50 in 2017, compared to 11% in 2008 (Public Health England 2018). Ageing and HIV is a recognised issue in the UK response, including by Public Health England (Yin, Brown et al. 2014, p.4):

One in four people living with a diagnosed HIV infection is now aged 50 years and over. This is due to improved survival and continued transmission and signals a need to develop services appropriate to an ageing population.

The age profile of women living with HIV accessing care has changed over time. As shown in Figure 1.1, older women constitute an increasing proportion of those accessing care for HIV.

Figure 1.1: Number of women accessing HIV care by age group, 2004-2014 (Chirwa, Ma et al. 2016)



Source: Data provided by Zheng Yin (Centre for Infectious Disease Surveillance and Control, Public Health England)

As the population of people living with HIV ages, the medical and social care needs of the patient cohort change. Increasingly, people living with HIV are requiring care for conditions not associated with their HIV, as shown in Table 1.1 below. This demonstrates the increase in co-morbidities that people ageing with HIV experience. It further highlights the growing need for hospitals and other

services to adapt to meet the needs of people living with HIV, where historically this may not have been an issue in their patient group. This is particularly true for gerontology and other services for older people, as the number of older people living with HIV has increased so significantly. It also reflects a change in HIV services. Historically, HIV clinics provided broad primary care to their patients, but now increasingly patients are expected to seek care elsewhere, due in part to more complex health needs in an ageing cohort (Keogh, Weatherburn et al. 2016).

Table 1.1: Count of finished consultant episodes where there was a (a) primary diagnosis and (b) secondary (excluding primary) diagnosis of HIV in England, 1998-99 to 2013-14.

Source: Hospital Episode Statistics (HES), Health and Social Care Information Centre

Year	(a) Primary diagnosis	(b) Secondary diagnosis (excluding primary)
1998-99	4,209	4,149
1999-00	5,141	4,809
2000-01	4,301	5,424
2001-02	4,648	5,593
2002-03	4,638	6,959
2003-04	4,743	8,053
2004-05	5,870	9,358
2005-06	5,435	11,598
2006-07	7,905	12,551
2007-08	7,452	13,914
2008-09	7,746	14,650
2009-10	7,178	16,439
2010-11	6,950	19,267
2011-12	6,992	20,227
2012-13	6,329	22,319
2013-14	5,618	24,252

In addition to health conditions not linked to HIV, older patients may experience faster HIV disease progression, and poorer responses to antiretroviral treatment (Pratt, Gascoyne et al. 2010). Treatment side effects and toxicity are also more commonly reported in older people, linked to higher rates of co-morbidities and treatment with other medications (Pratt, Gascoyne et al. 2010).

Women ageing with HIV can expect to experience healthcare needs linked to ageing in the same way as women not living with HIV, such as cancers, diabetes and frailty (Oursler, Goulet et al. 2011, Smit, Brinkman et al. 2015). In addition,

they may also experience conditions that are caused by long-term antiretroviral treatment and/or HIV itself, such as kidney and bone density problems (Gupta, Eustace et al. 2005). The psychological impact of ageing, mental health conditions and polypharmacy may also affect older women living with HIV (Power, Bell et al. 2010, Durvasula 2014, Winston and Underwood 2015). Additionally, they may experience social care needs due to mobility or physical health problems, or the impact of dementia or related conditions.

Many of these challenges are familiar to anyone ageing, but women living with HIV face additional layers of complication, due both to the addition of the HIV-specific health burden, and the social and psychological impact of HIV. Social isolation and lack of support may be an issue (Rosenfeld, Anderson et al. 2015). Experience or expectation of stigma and discrimination may present barriers to seeking or benefiting from care and support (Emlet 2006). Long-term diagnosed women may struggle to plan for and negotiate an older age they never expected to reach (Power, Bell et al. 2010). Recently diagnosed older women may also face challenges, as they negotiate older age with an unexpected HIV diagnosis. Whether HIV is a long-term or recent diagnosis, it influences and alters the experience of ageing.

Challenges associated with ageing are compounded by the overall challenges that women living with HIV face. Research in London suggests women living with HIV have three times the rate of poor treatment outcomes compared to gay men, with greater issues with adherence and a greater likelihood of a detectable viral load (Burch, Smith et al. 2015). This difference in treatment outcomes can be partially attributed to socio-economic factors, including poverty and unstable housing (O'Connell 2015). It may also speak to the ongoing stigmatisation of HIV in the wider community, which creates barriers for women accessing testing, treatment and care and limits sources of specialised support (Johnson, Samarina et al. 2015).

Through this thesis, these challenges will be explored, initially in the literature review in chapter two, to review what is available in the existing evidence base on the health and social care needs of older women living with HIV, and then in

detail through the voices and experiences of women living with HIV who have participated in this research.

1.2 Inclusion of women in HIV-related research and practice

For women ageing with HIV, I argue that there are additional obstacles around relative invisibility, and a lack of understanding of their specific needs and experiences. This includes, for example, coping with HIV alongside other ageing experiences such as menopause. This is in the context that sex and gender are often missing from health research, leading to gender-blind results and implementation with implications for women's health across health promotion, diagnosis, treatment and services (Olliffe and Greaves 2015). For example, despite two decades of efforts, women in the United States are under-represented in trials in cardiovascular disease and cancer, respectively the first and second biggest causes of mortality for both women and men (Mazure and Jones 2015). Women are also under-represented in HIV-related clinical research, accounting for just 19.2% of participants in studies of HIV treatment, despite being half the global population of people living with HIV (Curno, Rossi et al. 2016).

There have been efforts to improve the inclusion of women in research, as part of a broader trend which Epstein (2007) termed the 'inclusion-and-difference paradigm'. Epstein explores the trajectory of a growing focus on group identity in clinical research and health policy, and questions the extent to which social categories such as gender are meaningful clinical categories, and whether this approach can address health disparities. In the case of gender, he notes efforts to promote greater inclusion of women in research and disaggregation of data (Epstein 2007).

Epstein (2007) suggests that the 'inclusion-and-difference paradigm' is part of a wider feminist moment where, he argues, the primary battle for equality has been won, at least for those influencing over health policy, leading to a sense of safety in arguing for difference and different treatment. This is a somewhat sweeping claim, and I would argue that in the context of HIV specifically, the argument for greater inclusion of women in research and for greater disaggregation of findings

by sex has not primarily been made by the institutional actors Epstein identifies. Epstein's argument provides a relevant note of caution, especially the reminder that sex is not a simple binary given the prevalence of intersex characteristics, and that differences may be incorrectly attributed, leading to negative outcomes. However, in the case of HIV, there is evidence of differences in side effects, adverse events and efficacy of treatments (Scully 2018). This seems sufficient to support a sex-disaggregated approach, but one that is informed by Epstein's cautions about the wider causes of health disparities, particularly social and cultural factors (Epstein 2007).

The pattern of under-representation is also reflected in HIV-related social research, and there is recognition of barriers to the recruitment of women. A study conducted in Canada explored researcher perceptions of barriers to recruiting women living with HIV (Loutfy, Kennedy et al. 2014, p.58):

The highest ranked recruitment barriers identified were: sensitivity of the research topic (59%), time/availability constraints (59%), language barriers (53%), HIV disclosure/stigma issues (47%), lack of trust of research personnel (41%), fear of research (41%) and inaccessibility to child care and transportation (41%).

Barriers to recruiting women living with HIV are a longstanding issue that require focused attention and further research (Loutfy, Kennedy et al. 2014).

With respect to ageing with HIV, there is relatively little attention to or understanding of the needs of women, and of the diversity within that group, as one 66-year-old woman living with HIV said in a newspaper interview (Tucker 2015):

"I'm just wrong for HIV: female, 60s, middle class. Some people can't deal with it."

In my research, I explore how women are adapting and responding to their health and social care needs as they age with HIV, with a specific focus on the experiences of women living with HIV aged 50 and over in London. I adopt a gendered and assets-based approach, using qualitative methods including participatory creative workshops, participatory literature review and data analysis, semi-structured interviews with key stakeholders, and life story interviews with older women living with HIV. An assets-based approach understands individuals and groups as possessing positive health and wellbeing promoting assets. Using

an assets-based approach, I will explore the role of the individual in defining and meeting their own needs (Brooks and Kendall 2013). Participation and participatory research methods are used throughout.

Through these methods, I explore the experiences of women growing older with HIV, with a particular focus on coping and strategies to address needs, and the role of community in providing support, including practical, social and emotional support. Through women's narratives of ageing, coping and thriving with HIV, stories of personal connections, participation, resilience and persistence emerged, which defined a form of coping that draws on third-sector and State support, but consists primarily in community and belonging. Through the use of innovative methods and detailed exploration of the experiences of women ageing with HIV, I provide deeper insights into these experiences as well as novel understandings of how community and communitarian discourses emerge and are utilised. Identifying both needs associated with ageing with HIV, and coping strategies and support developed to meet them, I situate these findings within a wider context of current health and social care models and provision, and explore how needs are being met, in order to offer recommendations for improvements in policy and practice.

In addition to this empirical study, I consider in detail methodological and theoretical positions and approaches to develop a research framework for this study. In so doing, I consider the epistemological conditions of the production of knowledge in other research around women, ageing, and HIV, and seek to take a different approach to yield different knowledge. The contribution made by this thesis is these different results. Through this research I have generated new insights into women's experiences of ageing with HIV, including how they are adapting to needs and experiences associated with older age with a stigmatised condition, and how community functions in this process.

1.3 Research Aims and Framework

My research contributes to a growing body of literature on ageing with HIV, and fills gaps in that literature specific to women. The evidence base on ageing with HIV is expanding, especially in clinical research. There is comparatively less

social research being undertaken, a space this research seeks to fill. More, by exploring gendered experiences of ageing with HIV, while giving voice to women's own experiences and their adaptations and strategies to meet their growing and changing needs, both individually and through communities, this research differs from other existing studies. HIV research in the UK is shaped by an epidemiological approach focussed on the two most affected groups by HIV transmission route: men who have sex with men, and African heterosexual men and women. Consequently, there is less research focusing on women as a group (of all ethnicities) and that explores women's differing identities across race, ethnicity, sexual orientation and gender identity. The needs and experiences of women as a distinct class and group in the context of HIV are under-researched in the UK overall (Sophia Forum and Terrence Higgins Trust 2018). In relation to ageing and HIV, women's experiences are largely absent from the research literature. This thesis aims to contribute to filling that gap.

Major UK studies of ageing and HIV have indicated a range of challenges associated with managing HIV in later life, including stigma and related barriers to disclosure, access to services and support, socio-economic issues and physical and mental health problems. (Power, Bell et al. 2010, Rosenfeld, Anderson et al. 2015, THT 2017). Of these cited studies, the first two, *50 Plus* and *HIV in Later Life* (HALL), did not analyse the specific experiences of women as a group (Power, Bell et al. 2010, Rosenfeld, Anderson et al. 2015). The later study, *Uncharted Territory*, did separate out analysis on women, but did so based on a survey which, like the earlier *50 Plus*, was developed by a third sector organisation with a mandate to provide services, and so prioritised an exploration of need (THT 2017).

Collectively, these studies provided an invaluable baseline to explore the needs of people ageing with HIV and helped shape the key issues explored in this research. There are however significant gaps, which my research addresses. Through taking a gendered approach, this study ensures that the needs and experiences of women as a group are explored. Additionally, *50 Plus* and *Uncharted Territory* focused on concerns about ageing and expected needs and challenges, allowing less space to consider responses, adaptations and coping; the assets-based approach of this research attempts to address these gaps.

Both HALL and *50 Plus* suggest that the uncertainty many people experience around the clinical impact of ageing with HIV is compounded by uncertainty about the social experience of growing older with HIV. In the existing literature on ageing and HIV, a ‘future forecasting’ approach is often adopted, in which participants are asked to share their concerns and to anticipate the challenges they expect to experience as they age. This risk-focused approach has three major limitations. First, it leaves out the experiences of those already in their older age. In reality, many people in their sixties and beyond are living with HIV. The lived experiences of these individuals are a vital resource in understanding how people adapt to needs related to HIV and ageing, and how they and their community (however they define it) have innovated to meet these needs.

Second, it adopts a needs-based, deficit model, which leaves little scope or space for positive adaptations or experiences. In this research, I therefore adopt an ethnographic engagement rather than a forecasting approach, inviting women not only to share their future worries, but to explore their identities and experiences with HIV as one strand in a wider narrative.

Third, it creates a template in which HIV is assumed to be a causal or contributory factor in future anticipated challenges, which is particularly the case in the *50 Plus* study, where participants framed experiences around employment, housing, benefits and other issues within an HIV context that is unquestioned. One neglected area I explore in this research is the extent to which HIV does play a role in influencing the socio-economic experiences of ageing.

Further, all three studies are largely descriptive studies of the experiences of older people living with HIV. By contrast, this research explores broader sociological issues such as the role and construction of community.

In seeking to explore the experiences of an under-represented, diverse and frequently invisible group, I adopt a feminist, reflexive practice of research as a form of advocacy, originating in an activist position that I argue is essential to adequate research with this population. More traditional social scientific approaches alone are insufficient to understand the experiences of women ageing with HIV. Not only do they limit representation in research, such

approaches fail to include the breadth of these women's experiences and, therefore, may not produce findings that are useful in practice in women's lives.

Speaking at the British Sociological Association annual conference in April 2018, the academic Akwugo Emejulu described the "epistemic injustice" affecting who gets to speak, be heard and produce knowledge. Speaking about women of colour involved in anti-austerity activism, Emejulu outlined how the struggle to be seen outside the frame of victimhood and 'otherness' enacted the "violence of invisibility" against those excluded from epistemic production. In this thesis, I argue a similar frame applies to the experiences of women living with HIV, who are subjected to this same "violence of invisibility" as they are excluded at different levels.

Emejulu and Bassel (2018) present a model of advocacy through which women who are invisible and made 'other' come together through a shared sense of 'care' which opens up space for advocacy and for collective action (Emejulu and Bassel 2018, p.114):

For these activists, we can think about care as both a praxis – theory informed action – and as prefiguration – a process of becoming and creating new political subjectivities. To understand care as praxis is to recognize how *caring about Others* is a radical act. *To care about Others* requires the development of a political imagination that takes seriously the lived experiences of the most marginalized.

Emejulu and Bassel (2018) suggest that this process of becoming makes possible collective and political action and solidarity. I explore how the principle of 'care for others' underpins the collective and communitarian experiences of women living and ageing with HIV and their participation in advocacy. This contrasts with concepts of therapeutic or biomedical citizenship in the context of HIV, in which access to and relationships with treatment define an individualised model of engagement linked to HIV (Nguyen 2010, Paparini and Rhodes 2016). The ways and extent to which these different forms of community and participation are present and mobilised in different ways in women's lives, are explored in this thesis.

I also suggest that this principle of 'care for others' requires an advocacy approach to research which upholds the same values of care that, as Emejulu and Bassel (2018, p.115) further observe, involves "rejecting neoliberal, racist,

sexist, xenophobic, homophobic, ableist frameworks that govern [their] everyday lives". The practice of 'research as advocacy' underpins this thesis and the original contribution to knowledge that it offers. In subsequent chapters, I describe how women living with HIV have lacked voice and visibility in both wider social discourse and within HIV specific discourse in the UK context, a double jeopardy of exclusion due to perceived deviation from acceptable norms, or minority or 'other' status. To counter women living with HIV invisibility, this research prioritises and centres women's voices, experiences and narratives.

This advocacy approach is underpinned by my own background as a researcher. I have worked in HIV research, policy and advocacy since 2009, with a focus on gender and women through much of that time. I am actively involved in advocacy for women's rights in the HIV response, and this influences my approach to research. Specifically, I am committed to social change, and to research that contributes to achieving this. My interest in ageing grew from contributing to two studies, which had gaps around the inclusion of women as a distinct group of analysis (Power, Bell et al. 2010, Beer, James et al. 2014). This led me to pursue further study to address these gaps.

This research explores both the social and ecological, focusing both on HIV itself and the social implications of it. It therefore adopts a social, constructivist ontology, and reaches beyond this to explore the impact of HIV as a non-social actor. This demands a theoretical perspective that allows for interpretation, and in this case a feminist approach is adopted. The theoretical framework is defined in detail in chapter 3.3. I utilise a feminist approach that draws on an epistemology which centres subjectivity and privileges story as a form of data (Nadar 2014). This is applied with the recognition that the practice of research is often messy, and rarely adheres to 'off the shelf' theoretical paradigms but that theory can adapt to incorporate this messiness (Childers, Rhee et al. 2013).

In my personal and professional life, advocacy came before research. Through my work with women's rights organisations, I recognised that women's under-representation in, or even exclusion from, the evidence base is a significant barrier to effecting meaningful change to better meet their needs. Research which centres the excluded, and explores the ignored, is imperative for social

transformation and is a form of advocacy in itself. As a feminist researcher, the desire to enact social change is core to my research praxis and reflects a broader school of thought around the interaction between research and activism. Activist research has been defined as research that (Hale 2001, p.13):

a) helps us better to understand the root causes of inequality, oppression, violence and related conditions of human suffering; b) is carried out, at each phase from conception through dissemination, in direct cooperation with an organized collective of people who themselves are subject to these conditions; c) is used, together with the people in question, to formulate strategies for transforming these conditions and to achieve the power necessary to make these strategies effective.

This type of research requires involving participants at each stage from developing research questions and objectives to data collection, analysis, dissemination and validation, a process which I followed in this study (Hale 2001). Zerai (2002) defined three approaches through which researchers can contribute to social change. These are: contributing to and influencing practice and current debate in academia; working as consultants to provide academic expertise and insights to activists at community and grassroots levels; and, applying knowledge through direct engagement and advocacy activities (Zerai 2002). My research makes contributions in all three ways.

The 'research as advocacy' model also influenced my feminist approach. Feminist research emerged as a critical reaction against positivist approaches, and is rooted in the premise that traditional approaches conducted in the absence of a critical understanding of gender and its social function deny women voice and fail to capture their experiences (Holloway and Wheeler 2010). A feminist approach seeks to provide an alternative to dominant research approaches and epistemologies, by centring participants, adopting participatory approaches, analysing structural factors and inequalities, and taking a less hierarchical approach that recognises and seeks to redress the power imbalance between researcher and participant wherever possible, in part through reflexivity. Utilising this approach in conducting the research, I have used theory and methodological approaches in a pragmatic way, adopting that which is useful, adapting and developing in practice, and letting go of aspects that do not fit. My approach is outlined in more detail in chapter four of this thesis.

The main research question explored in this study is:

What are the experiences of women ageing with HIV in London? How are these experiences understood and expressed?

With further sub-questions:

- How are these experiences mediated by gender, sexuality, ethnicity, migration status and experiences, or other factors?
- How have women adapted to ageing with HIV, including experiences of age-related conditions and other co-morbidities, home and residential care, and economic and social issues?
- What assets do women hold and use to mediate their experiences, and in what ways are they used? Is the notion(s) of 'community' amongst these assets?
- How is the concept of 'community' relevant? What constructions of 'community' can we discern in the experiences, accounts given and discourses employed by older women living with HIV?
- How have collectivities of older women living with HIV, and others, responded to growing older with HIV, for example, through peer support and activism? Does this suggest a 'biomedical citizenship' and how might this function? How does this counteract or mediate notions of 'community' for women living with HIV?

Participants were recruited to reflect the diversity of women living with HIV in London and as far as possible to include diversity in terms of ethnicity, country of origin, migration status, socio-economic status, sexuality, length of diagnosis, relationship status, motherhood experiences and ability. The research was conducted in London, because it is home to the majority of people living with HIV in the UK, and the majority of HIV peer support and other service provision (Skingsley, Kirwan et al. 2015). The experience of ageing with HIV outside London, particularly in smaller urban or rural areas, is likely to be quite different and is outside the scope of this study.

The approach adopted is designed to address the challenge of women's under-representation in the evidence base on HIV and ageing. So little is currently known about women's experiences of ageing with HIV that a focus on this

specifically is justified, rather than comparative studies (for example with men, or with women with other health conditions). I would suggest that an exploration of this first is required, before meaningful comparative approaches can be feasible.

Further, HIV itself is often understood as different to other health conditions, due to the stigma associated with it. As my work is concerned with the subjective experience of living and ageing with HIV, it necessarily engages with this paradigm of stigma. From the outset of the epidemic, before the virus had a name, test or treatment, the association of HIV with stigmatised populations, especially gay men, sex workers and drug users, led to a stigma attaching to the condition itself (Fowler 2014, UNAIDS 2015). This was compounded by fear of the virus, especially when transmission was not understood, leading many to fear even normal everyday contact with those living with HIV (Sontag 1990). This fear led to direct discrimination, and fomented stigma that continues to affect people today, even now so much more is known about HIV.

The understanding and conceptualisation of HIV does have commonalities with other conditions that elicit stigma, as Sontag (1990) observed in relation to cancer and tuberculosis. She describes how illnesses are constructed metaphorically, for example with military metaphors that involve 'fighting', 'wars against' specific conditions, and the impact this necessarily has on affected patients who become associated with 'otherness' and 'guilt'.

Stigma here arises from the constructed understanding of the illness itself, as reflecting the character or value of those it affects, and speaking to their failure to do or act as they ought to, in the narrative of a societal battle against an invading foe (Sontag 1990). Despite advances in knowledge about HIV, the language of 'ending AIDS', 'fighting' and 'quests' continues to be used (UNAIDS 2017)

For women, who in the Western world were not associated with AIDS in the early days as these metaphors and stigmas formed, they nonetheless have a lingering impact (Sophia Forum and Terrence Higgins Trust 2018). The sense of blame, of HIV as a consequence of having done what one ought not to have done, continues, and shapes the experiences of those living with the condition. Women face this stigma, compounded and augmented by gender stereotypes of appropriate behaviour, and older women experience ageist assumptions layered

on top. This complexity, and this inter-layering of sex and sexual behaviours, identity and risk, renders the experiences of HIV distinct, and so necessitates a focused exploration.

1.4 Thesis contents

This thesis presents findings and analysis from a multi-stage qualitative research project exploring women's experiences of ageing with HIV. The research presented in this thesis has been conducted in different stages, running roughly in sequence but with some overlap:

- 1) Empirical and participatory literature review (chapter two). The empirical review on HIV and ageing used a structured/systematic approach and key word/term searches in online research databases. Soft resources and grey literature were also consulted. Drawing on these two distinct forms and sources of knowledge about ageing and HIV – the formal peer reviewed evidence base, and outputs originated in the community defined as 'grey literature', allows for a broader picture to emerge of the current knowledge base on ageing and HIV, and enables a critical engagement with both the formal evidence base and with prevailing research approaches. The inclusion of grey literature is underpinned by the assets-based approach adopted.

The empirical review included a participatory literature review, a methodology I developed to involve women living with HIV in the analysis stage of the empirical review. Participation and experiential knowledge in the interpretative phase of the review responded to the challenges of a limited evidence base and represents an innovation in methodology contributed by this thesis.

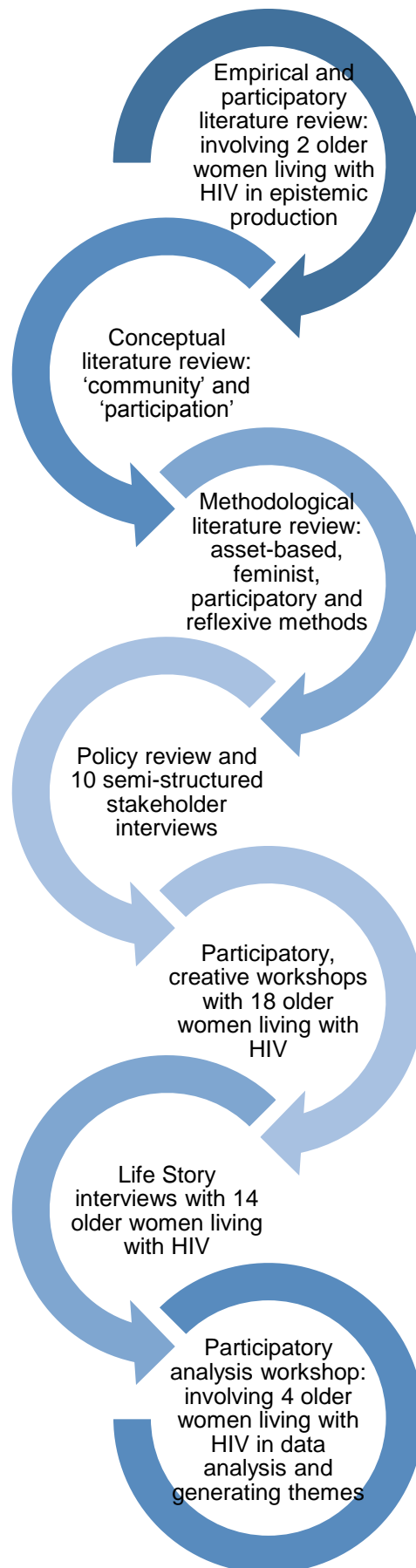
- 2) Theoretical and methodological literature reviews (chapter three and four). The theoretical literature review explores and critically engages with key concepts, including 'community' and the construction and understanding of communities in the context of HIV and 'participation', and what it means within HIV research specifically and research more broadly, as well as advocacy.

The methodology review considers assets-based and gendered approaches, participatory methodologies, reflexivity and life story interviews.

- 3) Participatory, creative workshops using body mapping and participatory methodologies to explore women's experiences (methods in chapter six, findings in chapters seven, eight and nine). This builds on the feminist and assets-based approach adopted and was shaped by the methodology literature review.
- 4) Policy review, and ten stakeholder interviews, including women living with HIV, clinicians, researchers, service providers and policy specialists, to explore models of clinical and social care provision, existing policy and how it is operationalised, and expectations of future needs related to ageing (chapter five). The semi-structured interview guide was informed by the empirical literature review, including the participatory review.
- 5) Life story interviews, with fourteen women living with HIV aged 50 and over (methods in chapter six, findings in chapters seven, eight and nine). The prompts used for these reflected insights gained through the previous phases of research but retained flexibility to allow for the priorities and experiences of participants to shape the content of the interview. Life story interviews form a major element of the work, a methodology chosen as it promotes the voice of participants and ensures that their own priorities, meanings and conceptual frameworks emerge.
- 6) Participatory analysis workshop to undertake collective interpretation of the research findings (chapter six). This workshop included four participants, all women living with HIV aged over 50, who reviewed transcripts and participated in open coding and discussion to generate and explore themes from the research data, informed by their own lived experiences.

The interlocking phases of the study are outlined in the flow chart that follows.

Figure 1.2 Visual diagram of study



2. REVIEW OF EMPIRICAL LITERATURE

In this chapter I present an overview of the empirical literature on women, ageing and HIV, beginning with a narrative overview of the clinical literature, and moving on to a systematically approached review of the social science literature. As part of the latter, I conducted a participatory literature review, involving older women living with HIV in analysing and drawing conclusions from the literature, discussed in section 2.5.

This chapter, and indeed this research, focuses exclusively on HIV, ageing, and women. Whilst comparative study with other groups, younger people, or women with other long-term conditions, might all be worthwhile subjects to explore, it is beyond the scope of this study. Some research to compare experiences of HIV with other chronic conditions has been undertaken, for example, one recent study found psychosocial adaptation to their condition was similar for patients ageing with HIV to those ageing with other conditions (Ronel, Dinkel et al. 2019). While this is a growing area of study, as this chapter will demonstrate, the experiences of women ageing with HIV are insufficiently explored and understood and so warrant focused attention.

2.1 HIV and Ageing – introduction and the clinical picture

The clinical evidence base on ageing with HIV has grown significantly in recent years. The following summary is based on a review of materials from databases, conferences and reference lists. It provides a broad overview of the field rather than a comprehensive summary. For included articles, I reviewed abstracts and full papers, as required, and tabulated key findings by theme. The review includes studies with male or male and female participants, as there is little evidence available that focuses only on women, symptomatic of a wider gap in HIV research (Haberl, Johnson et al. 2013). However, it excludes issues that only affect men, such as male biology or sexual function. Findings are grouped by thematic area.

Overview

Ageing with HIV is as complex as ageing itself, so a broad overview is a helpful foundation. Research on ageing with HIV includes many different diseases and health issues. One patient guide to ageing with HIV covers psychological health, smoking, diabetes, kidneys and sexual functioning, indicating the range of issues that are relevant (JUSTRI 2013). My thesis considers how complex co-morbidities and varied biological experiences intersect with women's experience of HIV and coping with it. A review of the literature exposes gaps where older women's experiences are not fully accounted for.

A review of a UK cohort of 3258 people living with HIV, including 637 women, compared experiences of physical symptom distress, depression, anxiety and health-related functional problems across age groups (McGowan, Sherr et al. 2016). The review found that there was no trend between age group and physical symptoms; however, the prevalence of depression and anxiety decreased with age and functional problems increased with age. The authors conclude that length of HIV diagnosis, rather than age, is the most significant factor influencing both psychological symptoms and poor quality of life (McGowan, Sherr et al. 2016).

Much of the available evidence focuses on people who have lived long-term (over decades) with HIV, with associated long-term impacts of both HIV and treatment. There are also, however, particular challenges for older adults who are diagnosed with HIV in older age. A review of UK data found that people diagnosed aged 50 and over were more likely to be diagnosed late than those under 50, and that late diagnosis was linked to an increase in short-term mortality, which was 14 times higher in older people diagnosed late (Smith, Delpech et al. 2010).

With specific respect to women, evidence is limited. Guidelines for the care of older (defined as over 50) and post-menopausal women living with HIV published in the US acknowledge that available information is limited but note a few key generalisations (New York State Department of Health AIDS Institute and Johns Hopkins University Division of Infectious Diseases 2008). These include: older age is associated with increased disease progression, which can be managed by treatment with ART; side effects and direct symptoms of HIV can be difficult to

distinguish from common age-associated factors such as anaemia; and due to increased risk associated with HIV, there is a greater need for screening and vigilance for malignancies including cervical, ovarian, breast and uterine cancer (New York State Department of Health AIDS Institute and Johns Hopkins University Division of Infectious Diseases 2008).

A review of care provided to older women living with HIV suggest that there are significant rates of co-morbidities and premature or early menopause, and recommended improvements in care including: “yearly cervical cytology, early counselling with regard to reproductive options, menopause management and screening for sexually transmitted infections (STIs)” (Samuel, Welch et al. 2014).

General health and co-morbidities

Co-morbidities are common in people ageing with HIV. One study found that by 2030, due to ageing, 84% of people living with HIV will have at least one non-communicable disease co-morbidity, compared to 29% in 2010, and 54% will be prescribed co-medications, up from 13% in 2010, with 20% taking three or more co-medications (Smit, Brinkman et al. 2015). This is likely to increase further in the oldest age group, with those over 75 more likely to experience undernourishment and age-related co-morbidities (Allavena, Bernaud et al. 2016).

Increased rates of co-morbidities and age-associated conditions mean many older adults living with HIV are taking multiple medications. As well as the challenges of managing multiple treatments, this increases the risk of drug-drug interactions, leading to difficulty in prescribing effectively for older people (compounded by additional risks of increased drug exposure and possible links to toxicity) (Winston and Underwood 2015). Age impacts on pharmacokinetics, particularly absorption, distribution, metabolism and renal elimination, with implications for the efficacy and toxicity of treatment (Boffito 2015). Researchers have called for more studies to determine the difference in pharmacology and toxicity in older patients with HIV and to develop targeted treatment guidelines, though without further acknowledging sex-based differences in pharmacology that should also be considered (Grabar, Weiss et al. 2006, Gebo and Justice 2009).

Decline in physical function is higher amongst patients with HIV compared to those without HIV, and this is increased by age-associated co-morbidities such as chronic pulmonary disease (Oursler, Goulet et al. 2011). HIV has been linked to earlier ageing and increased risk of frailty at an earlier age (Oursler, Goulet et al. 2011). Some have concluded that this accelerated ageing of the immune system essentially leads to people living with HIV 'ageing quicker' and developing frailty and conditions associated with older age at an earlier time (Rickabaugh, Kilpatrick et al. 2011). One study found HIV is independently associated with twice the risk of frailty in middle-aged people living with HIV compared to those without HIV (Kooij, Wit et al. 2016). Increased rates of frailty may also be linked to inflammation, which is associated with cardiovascular disease (Matin 2015).

A US study found that the incidence of a number of non-AIDS defining cancers was higher among patients with HIV than the general population (Patel, Hanson et al. 2008). Increased risk of cancer could be linked to lifestyle factors or the impact of a suppressed immune system. A study specifically among women found significantly increased risks for non-AIDS defining cancers (Fordyce, Wang et al. 2000).

Abnormal kidney function is commonly associated with HIV, affecting up to 30% of patients, but there is a lack of evidence to understand how this is caused and best treated (Gupta, Eustace et al. 2005). A Danish cohort study found impaired renal function was significantly higher among people living with HIV compared to a control group (Schouten, Wit et al. 2014).

HIV is associated with reduced bone mineral density and increased risk of bone fractures (Brown, Ruppe et al. 2004, Collin, Duval et al. 2009). Initiation of HIV treatment is associated with a 2-6% decrease in bone mineral density over two years, similar to the decrease associated with menopause, leading to a recommendation that HIV be considered a risk factor for bone disease, with screening of all post-menopausal women living with HIV (McComsey, Tebas et al. 2010).

HIV is a risk factor for heart failure (Butt, Chang et al. 2011). People living with HIV had twice the risk of heart attack as those in a matched control group in one study, with particular ART drugs associated with greater risk (Durand, Sheehy et

al. 2011). Heart attack and cardiovascular risk factors were found to be higher in people living with HIV compared to patients without HIV, especially for women, in a US cohort study (Triant, Lee et al. 2007).

A US study found a “substantial and significant” increase in patients hospitalised for stroke who also had HIV between 1997 and 2006, with a decrease in the overall number of strokes but an increase in strokes with coexisting HIV (Ovbiagele and Nath 2011). The same study found the average age for stroke was lower amongst people living with HIV. Another study found that as well as higher rates of stroke amongst people living with HIV overall, highest incidence was amongst women (Chow, Wilson et al. 2016).

Mental health and sexual functioning

Poor mental health is a significant risk for older people living with HIV, linked to stigma, uncertainty and the stress of managing the health and social aspects of HIV (Power, Bell et al. 2010). Older people living with HIV experience more depression, suicidal ideation and stigma, and HIV can also affect neurocognitive function, which is under-researched but evidenced amongst women (Durvasula 2014). Factors influencing mental health and wellbeing include care (both provision and receipt), access to healthcare, managing other health conditions, finances, relationships and other stress-causing influences (Durvasula 2014).

Early findings from the POPPY study, a large UK study comparing cohorts of younger and older people living with HIV to matched HIV negative control groups, indicate significantly higher rates of depression in people living with HIV aged over 50, at almost 50%, compared to just under 20% in the matched control group (Winston 2017). A sub-study exploring cognitive function found a slight difference between the HIV positive and matched groups, but that differences in cognitive function remain steady over time.

In a study conducted among men who have sex with men, researchers found that social support was associated with increased wellbeing and decreased stress, and that this impact increased in older men (Chesney, Chambers et al. 2003).

A study among people living with HIV in Portugal, comparing responses on a quality of life (QoL) assessment between older and younger people, found

middle-aged and older people reported significantly lower quality of life in the domains of independence, social relationships and physical health (Monteiro, Canavarro et al. 2016).

HIV is associated with greater problems with sexual functioning for women, which is further affected by menopause and symptoms of depression (Wilson, Jean-Louis et al. 2010). The impact of problems with sexual functioning may be compounded by reticence among healthcare workers to discuss sex with older patients. One study found GPs were not comfortable to raise issues about sex with older patients, based on stereotypical views about appropriateness and age (Gott, Hinchliff et al. 2004).

Menopause

Research in HIV and menopause is relatively limited, but a three-year study in the UK, PRIME, has greatly expanded the evidence base. The study found high prevalence of symptoms (including hot flushes, sexual problems and depression) among women living with HIV experiencing menopause, with women reporting a lack of information to prepare for menopause, and low use of hormone therapy (Tariq 2018). Specific HIV-related challenges of menopause included distinguishing and attributing symptoms to HIV or menopause, barriers to accessing appropriate care and the effect of menopausal symptoms on HIV management (e.g. treatment adherence) (Tariq 2018). Almost 90% of PRIME respondents experienced somatic symptoms, defined as hot flushes, joint and muscle pains and disruption to sleep and almost half were experiencing psychological distress.

HIV is potentially associated with early onset of menopause, with one study finding that women living with HIV were 73% more likely to have early menopause than women without HIV (Schoenbaum, Hartel et al. 2005). However, an analysis of data from the POPPY study, comparing women in the UK living with HIV with a control group of HIV-negative women, found no association between HIV and either age at menopause or menopausal status (Tariq, Boffito et al. 2016). HIV has though been linked with more “prevalent and pronounced” symptoms of menopause (Andany, Kennedy et al. 2016).

A narrative review of literature on menopause and women living with HIV, conducted in association with the PRIME study, found there are significant gaps in the evidence base, with conflicting data on the association between HIV and early menopause, and a lack of clear evidence around HIV and increased menopausal symptoms, as well as qualitative evidence of the experiences of menopause of women living with HIV (Tariq, Delpech et al. 2016). The authors conclude that there is likely to be unmet health needs for women living with HIV in relation to menopause and that more and better data are required to address this (Tariq, Delpech et al. 2016).

Menopause is associated with a loss of bone density, which is also associated with antiretroviral therapy initiation, and compounds that risk (McComsey, Tebas et al. 2010).

Conclusion

There is evidence of a link between HIV and a range of health conditions, with risks increasing with age. There is insufficient research to be certain of the risks. A lack of women in studies and studies on women means there is even more uncertainty about the links between HIV, ageing and broader health outcomes for women. With respect to this research, it is clear that the biological experience of ageing with HIV is complex and full of unknowns. HIV is therefore perhaps a complicating factor in women's experience of coping with ageing. Whether this uncertain clinical picture mediates women's experiences, and how this might be so, is explored in this thesis.

2.2 Review of social scientific literature on the experience of ageing with HIV

In this section, I present a systematically approached review of the social scientific literature on women, ageing and HIV (Aveyard 2010). This approach ensures the review answers a clear question, considers relevant studies and critically appraises those included (Khan, Kunz et al. 2003).

2.2.1 Introduction

This review builds on an earlier review conducted for the *50 Plus* study, which reviewed literature and identified gaps in the evidence base and directions for future research (Paparini 2009). Paparini's (2009) review includes 44 pieces of literature published between 1999 and 2009 in the UK, the US and some European countries that had similarities to the UK. Research drew from a range of disciplines, primarily psychiatry, psychology and biomedicine. Sociology, anthropology and policy studies were also represented, although the author noted a lack of attention to ageing within them.

Paparini's key themes include "the invisibility and internal diversity of the older HIV population; the complexity of health and social care needs; the cumulative effects of stigma and ageism; [and] poverty and social exclusion" (Paparini 2009, p.3). Invisibility, she argues, is evident in the lack of research about the experiences of older people living with HIV, and in patterns of late diagnosis and non-diagnosis of HIV in older people. She suggests there is a need for more research on ageing and HIV overall, and calls for diversification of research to explore the experiences of different groups and account for gender, time of diagnosis and other factors. The review includes some US literature on women's experiences, and Paparini concludes that, given the differences in access to healthcare and social support in the US compared to the UK, further UK-based research is needed.

Another theme Paparini identifies is the complexity of health and social care needs. Specifically, she points to the difficulty in disentangling the impact of HIV, antiretroviral treatment, and age in health problems, and uncertainty around disease progression and mortality. Mental health, in particular, requires additional research due to conflicting evidence about the association between HIV, ageing and depression. The review found some research on wellbeing with a focus on participation in meaningful activities and access to social support. Directions for future research include the impact of aspects of ageing, such as disability or isolation, and the extent to which support for older people is available and meeting the needs of people ageing with HIV.

Paparini identifies HIV stigma and other intersecting discrimination as another key theme. HIV stigma, ageism, misogyny, homophobia and other discrimination intersect with and compound each other, producing, for example, age-specific HIV discrimination and HIV-specific ageism. This leads to greater invisibility. HIV prevention, for instance, may exclude older people by assuming they are not sexually active. Paparini suggests there is limited research on these issues for specific groups or communities, though her review found some US literature on older women that identifies the need for a gendered approach.

Finally, Paparini suggests poverty and social exclusion require further research. The very limited literature on the subject fails to identify potential issues around access to employment, pensions or state benefits, which represent directions for future research.

My own review builds on Paparini's *50 Plus* review of literature up to 2009, considering literature published after 2009 (and one earlier article not included by Paparini) and building on the same themes. Two articles included in Paparini's review were especially relevant to my own research questions.

The first, Emlet, Tangenberg et al. (2002), advocates for a feminist approach to social work practice for older women living with HIV, based on a support group-based qualitative study (Emlet, Tangenberg et al. 2002). The authors of this US study stress the need to address the invisible and unmet needs and specific experiences of older women living with HIV, including the intersection of ageism, sexism and HIV discrimination, in order to provide appropriate social care. Emlet, Tangenberg et al. (2002) suggest that gendered experiences, such as social pressure to prioritise care for others, poverty or other barriers, shape women's experiences and warrant a targeted response and a feminist approach (p.249):

Feminist perspectives are helpful in their attention to psychodynamic issues, cultural diversity, socioeconomic status, and gender-based institutional inequalities. To ascertain what resources are most appropriate for older women, it is important to gather information from the women themselves. Research methods that rely on group discussions and personal narratives, combined with what is known about at-risk and infected women through demographic data and larger quantitative studies, are necessary for the development of effective intervention strategies.

This resonates with the feminist orientation adopted in my study, which involved women living with HIV at each stage of research, to ensure that the findings reflect women's own stories and experiences and contribute towards developing effective responses.

With this in mind, this literature review is conducted and presented in two parts. The first is a systematically approached review of the literature on women, ageing and HIV building on the themes that emerged from the *50 Plus* review (Paparini 2009). The second, presented in section 2.5, is a participatory analysis of the review findings, in which women living with HIV analysed the themes emerging from the review to identify gaps and directions for further study.

This two-part approach ensures that each stage of my study is informed by the lived experience of older women living with HIV, and responds to the challenges presented by a limited evidence base. The methodology adopted for the participatory review is described in detail in section 2.5. One challenge of this approach is that it introduces time boundaries to the literature review. The review presented in the following sections was completed in March 2016, and its findings reflect literature published up to that time, as shared with the participants. It is not feasible, due to limited time, resources, and availability of participants, to reconvene the participatory review to gather input on literature published after March 2016. While later literature is included in an update provided in section 2.6, it did not go through the participatory review process.

The research question considered in this review of social science literature is:

What are the health and social care needs of older women living with HIV?

With specific reference to:

1. *Experiences of ageing and HIV*
2. *Needs described by older women living with HIV in published research (including mixed-gender samples)*

In addition to this research question, I also consider where and how women are included, or absented from, research, utilising a feminist theoretical framework.

2.2.2 Methods

The social sciences literature review was conducted using standard, digital research methodologies. I gathered material through hand searches and a keyword search of electronic databases, using EBSCOHOST under the grouping 'Health Sciences Research Databases'. This collective database includes: Academic Search Premier, MEDLINE, Psychology and Behavioural Sciences Collection, PsycINFO, SPORTDiscus and CINAHL Plus with Full Text.

The Boolean search terms used were: (HIV or HIV positive or human immunodeficiency virus or HIV infection) AND (aging or ageing or elderly or older adults or seniors or geriatrics) AND (women or woman or female or gender). This search returned 3723 results, which were narrowed to the years of publication 2009-2016, returning 2154 results.

To ensure no relevant research published in social science databases was excluded, I also ran a search with the same Boolean terms and date range in both the Taylor & Francis database and the SAGE publications database. Neither search produced any relevant results.

Initial inclusion criteria applied were: full text, scholarly (peer reviewed) journals, academic journals/journals, and English language. This led to 467 results.

The purpose of this review was to consider social scientific literature, therefore it includes qualitative primary research literature associated with public health, social support or psychological research. I excluded basic science, biomedical research, clinical research, and intervention evaluations. My interest is in qualitative, in-depth research conducted with women, so quantitative research was excluded. Mixed methods studies were included, in particular *50 Plus* and *HALL*, since they are the only UK research available. However, only the qualitative results of these studies were included in the review. Methodologies included were: empirical study, interview, qualitative study, focus group, and field

study. Excluded methodologies were: quantitative study, systematic review, treatment outcome/clinical trial.¹ This returned 55 results.

I screened abstracts against the inclusion criteria: qualitative primary research literature and research conducted in the UK, US, Canada, Australia, New Zealand and Western Europe², excluding research carried out elsewhere as the difference in circumstances and experiences between women in the UK and other geographical settings are too significant to allow meaningful insights to be drawn.

A table of results and screening outcomes is included at Appendix 1. Reasons for exclusion include country where the research was conducted, and methodology. In addition, studies focused on risk, prevention and acquisition were excluded.

Based on abstract review, six articles were identified for inclusion. In addition, two reports and three articles identified through hand searches and assessed against the inclusion criteria were included. Included articles were added to the EndNote reference manager and full text PDFs downloaded.

2.2.3 Results and critical appraisal

The final texts identified for full-text review to assess eligibility were:

- “You’re awfully old to have this disease”: Experiences of stigma and ageism in adults 50 years and older living with HIV/AIDS. (Emlet 2006)
- Older African Americans’ management of HIV/AIDS stigma (Foster and Gaskins 2009)
- “It’s a Hidden Issue”: Exploring the experiences of women living with HIV-associated neurocognitive challenges using a disability framework (Gallagher, Biro et al. 2013)

¹ Initially, additional methodologies also excluded were: longitudinal study, follow-up study, literature review, prospective study, retrospective study, meta-analysis, nonclinical case study. On reflection and after receiving guidance that these could include relevant qualitative work, I later re-ran the search with the same terms, date range and initial inclusion criteria and limited results to these methodologies. That produced 92 results. I then applied ‘qualitative research’ as an additional criteria to these results, which returned nine results. Of these: one was already included in the review; three were conducted in countries excluded from the review; two focused exclusively on men; one did not include HIV; and two focused on chronic pain management in the context of HIV, which is outside the remit of this review.

² Additional countries not included in Papparini’s review were also searched from 2009 on.

- HIV-positive mothers with late adolescent/early adult children: “empty nest” concerns (Murphy, Roberts et al. 2012)
- A national study of ageing and HIV (*50 Plus*) (Power, Bell et al. 2010)
- Intimacy and sexual decision making: exploring the perspective of HIV positive women over 50 (Psaros, Barinas et al. 2012)
- Social support, mental health, and quality of life among older people living with HIV: Findings from the HIV and Later Life (HALL) project (Rosenfeld, Anderson et al. 2015)
- Perceived Barriers to Social Support from Family and Friends among Older Adults with HIV/AIDS (Schrimshaw and Siegel 2003)
- The aging HIV/AIDS population: fragile social networks (Shippy and Karpiak 2005)
- Aging with HIV and disability: the role of uncertainty (Solomon, O'Brien et al. 2014)
- Taking It One Day at a Time: African American Women Aging with HIV and Co-Morbidities (Warren-Jeanpiere, Dillaway et al. 2014)

After assessing full-text articles, all 11 results were judged to be relevant. I then critically appraised each text, using the critical appraisal tool for qualitative research developed by the Critical Appraisal Skills Programme (CASP 2013). See Appendix 2 for a summary and full critical appraisal of each paper.

All 11 papers were found to be of good quality, with clear research aims, relevant methods and clear presentation of findings, so were all included. Subsequently, each paper was thematically analysed using NVIVO 10 software, following the ‘research synthesis’ approach defined by Thomas and Harden (2008). Recognising that qualitative research is context-specific with limited generalisability, thematic analysis allows for research synthesis that goes beyond the reviewed studies to identify common themes in findings from multiple studies, through a process of free coding, and then generating descriptive themes and analytical themes (Thomas and Harden 2008). The findings of this process follow.

2.2.4 Gaps in current evidence base

The overall evidence base on women's experiences of ageing with HIV in relation to health and social care is limited. Whilst these 11 studies are all of good quality, only four focus exclusively on women. Of the remaining seven, many do not draw out women's experiences specifically in the analysis – true of both UK studies included (Power, Bell et al. 2010, Rosenfeld, Anderson et al. 2015). It is therefore challenging to understand women's experiences in particular.

None of the 11 included studies were participatory. One study, *50 Plus*, did include community researchers, but the final report does not discuss their participation (Power, Bell et al. 2010). Only three of the studies refer to advisory committees of people living with HIV (Power, Bell et al. 2010, Solomon, O'Brien et al. 2014, Rosenfeld, Anderson et al. 2015). Additionally, none of the studies discuss the relationship between researcher and participant, or reflexivity. This leaves a significant gap in the evidence base, considering the power-laden research dynamic and how it might affect participation in research.

The included studies divide into two groups. HALL and *50 Plus* are large UK studies with broad research focus. They are recent, conducted in the same geographic setting and include representative proportions of women participants; but, they do not consider participation, gender, or analysis of women's experiences as a group. The remaining are journal articles answering discrete research questions, conducted in different geographic settings. Based on this search of the literature, it is clear that there is a specific gap in terms of research that is participatory, gender-based and focused on women.

Also of note, seven of the studies were conducted in the US, often with samples exclusively or predominantly of African American women. These findings have limited transferability, due to differences in access to healthcare and treatment. Further, the impact of race and racism is likely a factor for women in the US and UK, but the African American experience and the migrant African experience in the UK are again dissimilar. Two of the studies were conducted in Canada, which has a public health system more similar to the UK, but the social experience of living with HIV may be quite different, given different social structures, indigenous experiences and migration patterns.

2.3 Analysis of review findings

Building on the themes identified in the *50 Plus* literature review (invisibility and internal diversity, complexity of health and social care needs, cumulative effects of HIV stigma and ageism, and poverty and social exclusion), and careful analysis of the 11 papers included in this review, I identified nine interlinked themes:

1. Social networks and relationships: intimate partners, family and friends
2. Mental health, wellbeing and coping
3. Care and social support
4. Loneliness and isolation
5. Stigma and discrimination
6. Health needs and co-morbidities
7. Socio-economic and practical issues
8. Disclosure
9. Ageism

These themes reflect the *50 Plus* themes but are broader and identify additional experiences that were absent from the earlier review. The themes are presented roughly in order of most to least common.

2.3.1 Social networks and relationships: intimate partners, family and friends

HIV can have a significant impact on both social networks and relationships, through discrimination or non-disclosure causing disruption to relationships, including preventing them from forming or continuing (Rosenfeld, Anderson et al. 2015). Linked experiences like migration can have a similarly negative impact.

Fears around the consequences of disclosure can prevent older people living with HIV from seeking and accessing support from friends, partners and family (Schrimshaw and Siegel 2003). For some, fear of burdening family or friends, or of exhausting limited supplies of social support, were barriers to asking for or accessing care and support (Schrimshaw and Siegel 2003).

2.3.1.1 Relationships with children – responsibility for and support from

Financial responsibility for children living in a country of origin can be perceived as a burden for migrant parents (Power, Bell et al. 2010). In such cases, the parental relationship does not represent a present source of practical or emotional support, given geographic distance. For participants in HALL who were migrants, HIV had disrupted their ability to fulfil their parental role, due to financial instability and geographical distance, which precluded them providing security and daily care to their children 'back home' (Rosenfeld, Anderson et al. 2015).

In *50 Plus*, worry for children, including about the potential for them to acquire HIV, caused concern and even mental distress (Power, Bell et al. 2010). In some cases, older women living with HIV reported having very young dependent children living with them – a reminder that, as more women become pregnant in later life, and with families founded in multiple ways, older people may still have young children. One 54-year-old woman participant described her concerns about providing financial security for her four-year-old child as she faced poor pension prospects and concerns around employment (Power, Bell et al. 2010).

Disclosure of HIV status was felt to have the potential to emotionally harm children, so disclosure had to be carefully managed to mitigate this, as well as ensure the child was old and/or mature enough to understand the information and to uphold confidentiality (Rosenfeld, Anderson et al. 2015).

Mothers with self-reported neurocognitive challenges suggested that caring for their children was a positive experience which helped them to self-manage HIV and their neurocognitive difficulties, and facilitated their continued participation in daily life (Gallagher, Biro et al. 2013). Similarly, participants in another study described having children, even adult children, who relied on them for support helped them to 'feel young' (Warren-Jeanpiere, Dillaway et al. 2014).

In a study of 'empty nest' experiences amongst women living with HIV, women described how adult children leaving home threatened their identity, which had been bound up with mothering (Murphy, Roberts et al. 2012).

2.3.1.2 *Intimate partners*

Intimate partners provide emotional support, and help with managing HIV and 'feeling younger' (Rosenfeld 2012, Warren-Jeanpiere, Dillaway et al. 2014). However, for black African participants in HALL, having a partner was associated with reporting poorer mental health. The report authors suggest this may be due to geographical distance from a partner (assuming the partner remains in the country of origin), and the challenges of managing financial responsibility for a partner when socio-economic status is difficult (Rosenfeld, Anderson et al. 2015). This is similar to the connection made in the *50 Plus* study between having children 'back home' and financial burden and worry. This highlights the importance of understanding migration journeys and where partners, children and other social connections are geographically, and how this mediates the support they can provide versus the burden they represent.

Where individuals had a partner at diagnosis, some participants described continuing that relationship due to fear about HIV preventing them finding new partners (Power, Bell et al. 2010).

In a study of intimacy and sexual decision-making, barriers to forming intimate partnerships were found to include stigma, disclosure and body image, and fears around HIV transmission (Psaros, Barinas et al. 2012). A similar pattern was reflected across all the included studies. HIV status appears to be perceived as a significant barrier to finding a sexual or romantic partner (Power, Bell et al. 2010, Murphy, Roberts et al. 2012, Rosenfeld, Anderson et al. 2015). This is often linked to an expectation or belief that forming a partnership necessitates disclosure of HIV, which is thought to risk negative consequences due to stigma and lack of knowledge about HIV. This is often associated with a belief that older people, who are most likely candidates for romantic partners, are less likely to be informed about HIV than younger people, and therefore more likely to hold ignorant, stigmatising views (Rosenfeld, Anderson et al. 2015).

In the HALL study, most partnered participants described supportive reactions to disclosure, but single participants anticipated a negative reaction to disclosure (Rosenfeld, Anderson et al. 2015). This suggests a disconnect between predicted

outcomes of disclosure and actual experiences, though this may be explained by people being successfully selective in whether and when to disclose to a partner.

One strategy to mitigate the risk of disclosure and stigmatising responses, is to form intimate partnerships with other people living with HIV (Rosenfeld, Anderson et al. 2015). Psaros, Barinas et al. (2012) found being in a relationship with an HIV negative partner would inevitably involve a power imbalance, and that HIV was a barrier to equal relationships unless the partner was also living with HIV.

In addition to HIV stigma, some women reported concerns that partners would associate their HIV status with behaviours that were socially stigmatised, such as 'promiscuity', sex work or drug use, and that these assumptions would be a barrier to forming relationships (Psaros, Barinas et al. 2012).

Body changes, linked directly to HIV, such as lipodystrophy, or to older age and menopause, and body image issues were also a barrier to forming relationships (Psaros, Barinas et al. 2012).

2.3.1.3 Parents

Sisters and mothers were most likely family members for disclosure in Emllet's study, and commonly found to be supportive (Emllet 2006). Where participants' parents were elderly, non-disclosure could be a function of what Emllet terms 'protective silence': avoiding disclosure to avoid negative consequences (Emllet 2006). One participant suggested it was unnecessary to disclose to her parents as she was confident that she would outlive them (Emllet 2006). This may suggest that disclosure is understood in instrumental or practical terms, where it is worthwhile only if it may lead to support or care in the future. Older relatives are unlikely to give this care, so disclosure is not worthwhile. In addition, the older age of parents or other family members of that generation prevents them from being able to provide practical support (Schrimshaw and Siegel 2003).

2.3.1.4 Friends

One study found having friends and an active social life were key to maintaining a good life (Emllet 2006). Friends, though, were not identified as an important group to disclose to, and some participants reported that they did not have any friends (Emllet 2006).

In their study of the social networks of older people living with HIV, Schrimshaw and Siegel (2003) found that friends were present in the majority of social networks and were seen as sources of support, and over half of these friends were also older people living with HIV. This reflects the findings of HALL, where participants described being able to access more informed, empathetic and knowledgeable support from others with experience of ageing with HIV (Rosenfeld, Anderson et al. 2015). This raises questions about access to practical support and care, as friends in similar health situations may have similar care needs and therefore be unable to offer support (Schrimshaw and Siegel 2003). This is perhaps reflected in findings that the need for more support with daily life and practical activities was greater than the need for more emotional support (Schrimshaw and Siegel 2003).

2.3.2 Mental health, wellbeing and coping

Many studies addressed mental health, wellbeing or coping. There is significant overlap between these three areas, but distinct themes emerged for each.

2.3.2.1 Mental health problems

50 Plus found disproportionate experiences of mental distress among African women, which the authors suggest may be linked to socio-economic challenges and migration experiences (Power, Bell et al. 2010). Participants described experiences of depression in multiple studies (Shippy and Karpiak 2005, Power, Bell et al. 2010, Rosenfeld, Anderson et al. 2015).

In a study on neurocognitive challenges, all participants reported feelings of depression, and many suggested this worsened their neurocognitive problems and created barriers to participating in daily life (Gallagher, Biro et al. 2013).

The HALL researchers suggest the extent of experiences of mental illness and issues such as self-harm, clinical depression and suicidal ideation, were 'surprising' (Rosenfeld, Anderson et al. 2015). These were linked to diagnosis, but also continued after that initial 'shock'. The mental health impact of HIV diagnosis itself varied by when participants were diagnosed (i.e. before or after the advent of effective treatment), knowledge about HIV at time of diagnosis and

experience of HIV before diagnosis (e.g. if friends or relatives had been affected by HIV or died of AIDS) (Rosenfeld, Anderson et al. 2015).

2.3.2.2 Coping strategies

Accepting HIV and learning to live with it, rather than focussing on it, was described as a coping strategy by participants in some studies (Foster and Gaskins 2009, Rosenfeld, Anderson et al. 2015). Having a positive outlook was also emphasised as assisting in managing HIV and associated challenges (Gallagher, Biro et al. 2013). Spirituality, beliefs and religion were also credited by participants with supporting them to cope with and manage their HIV (Foster and Gaskins 2009, Warren-Jeanpiere, Dillaway et al. 2014). Both studies where this emerged were conducted in the US with African American women, which may reflect a specific culture of religious practice and religiosity.

Participants dealt with ageing-related challenges such as forgetfulness by using coping strategies like list-writing and setting alarms (Gallagher, Biro et al. 2013). Coping for participants in HALL was affected by time of diagnosis, and the associated impact of HIV on the life course, with some suggesting that HIV had prevented them from having the older age they had expected, which affected their ability to cope with it (Rosenfeld, Anderson et al. 2015).

Coping with the impact of living with HIV, for HALL respondents, involved both drawing on existing social networks and developing new coping strategies including volunteering, exercise, and social activities (Rosenfeld, Anderson et al. 2015). Volunteering, supporting others and sharing skills allowed participants a sense of purpose and worth, creating a 'wise elder' role that was not otherwise available, because of disruptions to family networks as a result of HIV or migration (Rosenfeld, Anderson et al. 2015). Responsibilities for care and support for others, especially in parenting roles, also emerged as a coping strategy, as providing this gave a sense of routine and purpose (Murphy, Roberts et al. 2012). When this role was changing due to adult children leaving home, some women feared the impact this would have on their wellbeing, but others felt it might free up time to focus on themselves (Murphy, Roberts et al. 2012).

In Schrimshaw and Siegel's (2003) study, participants suggested self-reliance was a preferred coping strategy, based on values of independence and fear of burdening, or of depending on, others.

Attending HIV support groups was identified as a key resource for social support, friendship, romantic partnerships and to share knowledge and information to support others (Rosenfeld, Anderson et al. 2015). For others though, avoiding HIV-specific support was identified as a coping strategy, as it helped to decentralise the role HIV played in their lives (Rosenfeld, Anderson et al. 2015).

2.3.2.3 Wellbeing

Uncertainty, including around ageing with HIV, the long-term impact of treatment, ability to manage co-morbidities and neurocognitive challenges, and social support and care, all influenced wellbeing (Gallagher, Biro et al. 2013, Solomon, O'Brien et al. 2014). This also links with the episodic and fluctuating nature of HIV itself: as women are unable to predict how HIV will affect them at a given point in time, it is difficult to plan for care and support needs in the future (Gallagher, Biro et al. 2013).

In HALL, participants often identified their quality of life as subject to changes and open to improvement. The researchers identified a number of themes associated with good quality of life, including economic position, physical health, social networks and a positive outlook (Rosenfeld, Anderson et al. 2015).

2.3.3 Care and social support

This theme has some overlap with preceding themes, but is included separately as, across the reviewed studies, many participants spoke directly of their need for care and support, and of concerns around accessing it. I am defining 'care' as health and social care delivered when the individual is unable to manage the practicalities of daily living due to illness, disability or infirmity. Social support broadly encompasses emotional and practical support that everyone needs on an ongoing basis, which may fluctuate in type or amount required, but will always be a requirement in some form (Pearson 2019).

2.3.3.1 Care

Participants in *50 Plus* identified future care needs as a major concern (Power, Bell et al. 2010). The prospect of requiring formal care, including care homes, was a source of significant anxiety, with participants in multiple studies citing concern over discriminatory treatment from carers (Power, Bell et al. 2010, Solomon, O'Brien et al. 2014). In HALL, the authors note that although participants had concerns about health deteriorating and care needs increasing, few described plans or concerns around accessing care (Rosenfeld, Anderson et al. 2015). They attribute this to a focus on 'living in the present', rather than planning for the future.

2.3.3.2 Social support

In Scrimshaw and Siegel's (2003) paper, many of the older participants described themselves as dissatisfied with the amount of social support they received. More advanced HIV or longer length of diagnosis were both associated with more frequent feelings of receiving inadequate support (Schrimshaw and Siegel 2003).

Formal HIV support services, especially peer support groups, were frequently cited as vital sources of social support, particularly support that is informed by shared experiences (Power, Bell et al. 2010). However, some suggested that there was a need for more customised support, either for older people, for older women, or for those that are a minority within the population of people living with HIV (in this case white British people) (Power, Bell et al. 2010). Barriers to accessing formal support included mistrust of non-HIV specific services, lack of internet access for online services, and inaccessibility of support, including for example services being delivered in the evening when some women said they felt unsafe going out (Power, Bell et al. 2010).

Support from family and friends was often described as dependent on disclosure, which was a barrier to receiving it (Schrimshaw and Siegel 2003). In HALL, family, friends and work colleagues were described as sources of support, but participants often also sought out HIV peer support for the experiential knowledge peers could offer (Rosenfeld, Anderson et al. 2015).

Challenges to accessing social support from family included changes to relationships over time. For women whose children are reaching adulthood and leaving the family home, this can represent the loss of a significant, or even only, source of social support and practical assistance, making this a difficult period to navigate (Murphy, Roberts et al. 2012).

Participation in other formal activities or organisations also helped access to social support, including volunteering (Power, Bell et al. 2010) and church, in a Canadian study (Gallagher, Biro et al. 2013).

2.3.4 Loneliness and isolation

Loneliness and isolation recur frequently as themes throughout the included texts, linked often to small social networks and lack of social support (Schrimshaw and Siegel 2003, Shippy and Karpiak 2005, Emlet 2006, Psaros, Barinas et al. 2012, Rosenfeld, Anderson et al. 2015). In Emlet's (2006) paper, the majority of participants reported feelings linked to loneliness and isolation, whilst Foster and Gaskins' (2009) study identified several participants who described themselves as having no friends. Another study found many women who reported restrictions in their ability to participate in social or community life experienced loneliness and isolation as a result (Gallagher, Biro et al. 2013). Work and professional life were identified as important for providing a sense of self and purpose and facilitating social interaction, without which loneliness and isolation increased (Gallagher, Biro et al. 2013).

Experiences of loneliness and isolation led women to seek and value peer support and social contact with other women living with HIV, though this was not always available (Gallagher, Biro et al. 2013). Similarly, in the HALL study, participants reported feeling lonely and isolated due to limited social networks, and believed this to exacerbate mental health problems and restrict their ability to self-care (Rosenfeld, Anderson et al. 2015). Women who reported having chosen to abstain from intimate partnerships, through fear of stigma or rejection, described feelings of loss and loneliness resulting from this (Psaros, Barinas et al. 2012).

2.3.5 Stigma and discrimination

Stigma and discrimination, both actually experienced and, somewhat more commonly, anticipated, featured across many studies (Emlet 2006, Foster and Gaskins 2009, Gallagher, Biro et al. 2013). This often led to limited disclosure and 'protective silence', in Emlet's term, which in turn restricted access to social support and meaningful relationships (Emlet 2006). In a study of stigma experiences amongst older African American people living with HIV, some participants attributed not having experienced stigma to not having disclosed their HIV status to others (Foster and Gaskins 2009). Participants described accepting their HIV status as key to supporting them to manage stigma (Foster and Gaskins 2009).

In HALL, participants described stigma as having significant negative impact on quality of life (Rosenfeld, Anderson et al. 2015). More and better information about HIV, especially targeted to educate older people and those from communities less affected by HIV, was described as important to mitigate stigma (Rosenfeld, Anderson et al. 2015).

Stigma was also experienced on an ongoing basis, with participants in one study describing family and friends who were unwilling to provide social care due to fears around transmission through casual contact (Schrimshaw and Siegel 2003).

In some cases, discrimination came from other people living with HIV, who had internalised stigma to the extent that they discriminated against others, especially those who were publicly open about their HIV status (Power, Bell et al. 2010).

Medical professionals including GPs, nurses, and other healthcare staff were among the most commonly named perpetrators of discrimination by participants in *50 Plus* (Power, Bell et al. 2010). Anticipated stigma and discrimination from care providers was a barrier to accessing care (Power, Bell et al. 2010).

2.3.6 Health needs and co-morbidities

Participants in many studies described difficulties in managing HIV alongside other conditions, as well as with concurrent health-related needs such as menopause (Shippy and Karpiak 2005, Emlet 2006, Power, Bell et al. 2010, Rosenfeld, Anderson et al. 2015). While HIV was for most people effectively

managed by medication, side effects from treatment were a health issue in themselves, and other long-term health conditions were also common (Power, Bell et al. 2010, Rosenfeld, Anderson et al. 2015). The episodic nature of HIV made it more challenging to manage (Solomon, O'Brien et al. 2014).

Difficulty in ascribing symptoms to ageing, HIV, other conditions or menopause was common, and this uncertainty was challenging to manage (Power, Bell et al. 2010, Gallagher, Biro et al. 2013). This was compounded by uncertainty around the long-term impact of both HIV itself and of HIV treatment, which caused anxiety (Solomon, O'Brien et al. 2014, Rosenfeld, Anderson et al. 2015).

Managing HIV and adherence to treatment were felt by participants in another study to have become easier due to advances in medication, but managing co-morbidities was perceived by many as difficult, and requiring more effort to manage than HIV (Warren-Jeanpiere, Dillaway et al. 2014).

2.3.7 Socio-economic and practical issues

2.3.7.1 Work

Inability to work due to immigration rules was a financial challenge for participants in *50 Plus*, and also had consequences for social interaction, with a job perceived as a way to spend time with people regularly (Power, Bell et al. 2010).

Tiredness, managing health problems and side effects all represented challenges to continued working, with some suggesting they may have to cut their work hours, seek alternative employment or finish working earlier than planned, while others had already done so (Power, Bell et al. 2010). Fatigue, side effects and neuro-cognitive challenges were barriers to work for other participants, but they nevertheless described work as being positive and supporting their participation in daily life (Gallagher, Biro et al. 2013).

Unemployment and economic inactivity were much more common among *50 Plus* participants aged between 50 and retirement age, compared to the general population (Power, Bell et al. 2010).

2.3.7.2 Immigration

Insecure immigration status, and associated issues such as inability to work and the threat of deportation, were sources of emotional distress and challenges for some *50 Plus* participants (Power, Bell et al. 2010). Similar experiences were found in HALL, where participants also described volunteering and seeking support to distract from their immigration-related worries (Rosenfeld, Anderson et al. 2015).

2.3.7.3 Access to necessities

Managing bills, food and other daily costs was challenging for participants dependent on benefits and especially those relying on immigration-linked benefits in the UK (Power, Bell et al. 2010). The process of accessing benefits was seen as difficult, confusing and even humiliating where it required disability assessments (Power, Bell et al. 2010).

Some HALL participants described emotional distress and worry over access to food, housing and ability to pay bills. Some described having to sleep on the floor as they lacked adequate furniture, or missing meals in order to pay the bills (Rosenfeld, Anderson et al. 2015).

In the study of 'empty-nest' experiences, the prospect of adult children leaving home raised financial challenges due to the loss of their contributions to the household (Murphy, Roberts et al. 2012).

2.3.7.4 Finances

Life insurance, savings, private pensions and investments were all uncommon amongst *50 Plus* participants, especially black African women (Power, Bell et al. 2010). This lack of financial planning for later life was for many people a result of having expected to die early with HIV, which meant they had not made arrangements for their later years (Solomon, O'Brien et al. 2014). Participants were also less likely to own a home and more likely to live in social housing, compared to the general population (Power, Bell et al. 2010).

2.3.8 Disclosure

Disclosure is closely associated with relationships and social support, but also emerged independently as a source of uncertainty and concern. Levels of disclosure varied. In some cases, participants described being selective over which family members to disclose to, based on expectations of their reactions, including assessing their knowledge about HIV (Foster and Gaskins 2009). Choosing not to disclose was associated with expectations of stigma, the impact of internalised stigma and with concern that the person disclosed to would not maintain confidentiality (Schrimshaw and Siegel 2003, Foster and Gaskins 2009).

Participants in HALL described considering a person's age and social identity to assess their knowledge about HIV and decide whether to disclose to them (Rosenfeld, Anderson et al. 2015). In addition, the nature of their relationship to the individual, and whether or not they 'needed to know' about their HIV status, were factors that influenced disclosure decision-making (Rosenfeld, Anderson et al. 2015). Other people living with HIV were seen as the safest people to disclose to as they were expected to be non-stigmatising, informed and understand the need for confidentiality (Rosenfeld, Anderson et al. 2015).

Decisions about disclosure and worries over the consequences were, for HALL participants, the most distressing and challenging aspect of living with HIV as an older person (Rosenfeld, Anderson et al. 2015). They suggested it consumed a lot of time and energy and was a source of considerable ongoing concern.

Participants in Psaros, Barinas et al.'s (2012) study described disclosure as a responsibility to new sexual partners (in the context of transmission) and a source of worry and barrier to successfully forming sexual partnerships, which some participants avoided.

2.3.9 Ageism

In addition to HIV-related stigma and discrimination, some studies showed evidence of ageism (Emlet 2006). Emlet defines ageism as a cultural phenomenon played out through media and language that rests on discriminatory ideas that older people are less competent, intelligent, attractive and employable (Emlet 2006). Emlet (2006) found that many participants had experienced HIV

stigma and ageism in combination. The overlap between these two sources of discrimination suggests, Emlet argues, that they are linked. This could be due to discriminatory views of older people's sexuality and expectations of 'appropriate' behaviour of older people (Emlet 2006).

By contrast, in Foster and Gaskin's (2009) study, participants felt that stigma was not made worse by older age. However, in HALL, participants did feel stigma was made worse by ageism, and that views of HIV being associated with socially unacceptable behaviours were made worse by expectations of behaviour associated with older age (Rosenfeld, Anderson et al. 2015).

Participants in other studies also suggested that older people living with HIV received less sympathy and more stigma than younger people living with HIV, who were more likely to have their behaviour leading to HIV acquisition excused or tolerated (Schrimshaw and Siegel 2003, Rosenfeld, Anderson et al. 2015).

In two studies, the authors note that participants had used ageist language to describe themselves, suggesting internalised ageism (Emlet 2006, Rosenfeld, Anderson et al. 2015)

2.4 Discussion

In summary, this review of the social science literature on ageing, HIV and women found that personal relationships and social networks, mental health, wellbeing and coping, care and social support were key issues most frequently found in the literature. These were closely linked with additional themes of mental health and coping, stigma and discrimination, ageism, disclosure, loneliness and isolation, and were mediated by socio-economic and practical issues, health needs and co-morbidities. HIV as a medical condition was not the most significant challenge faced by older women living with HIV. Instead, the impact of HIV on personal relationships and social connections was key, and had broad impacts on wellbeing, quality of life and health, including mental health.

Turning to the research questions I posed at the outset of this review:

What are the health and social care needs of older women living with HIV?

With specific reference to:

1. *Experiences of ageing and HIV*
2. *Needs described by older women living with HIV in published research (including mixed-gender samples)*

It seems that the health and social care experiences of older women living with HIV include needs for social support, and for practical and emotional support in particular. The experience of ageing with HIV can be a difficult one, characterised by loneliness, isolation and uncertainty, coupled with difficulty managing co-morbidities and surviving economically. Experiences are varied, and limited UK research and gender analysis restricts the conclusions that can be drawn. In addition, the existing evidence base focuses primarily on needs, and there is little that accounts for women's coping or living well with HIV, indicative of the general focus on need in much health-related social research. While it is clear that need exists, there is a gap in the evidence base for literature which explores women's experiences of ageing with HIV with an assets-based approach, taking as a starting point not need, but women's experiences and how they describe them, which is my aim in this study.

From this review areas of support to explore include: negotiating disclosure; forming friendships; forming and sustaining intimate partnerships; financial advice and access to economic resources; access to cross-generational social support networks (mitigating the impact of limited access to practical support where friends and social contacts are predominantly similarly aged people also living with HIV); HIV-specific peer support and information and advice services; and, training and support for age-specific and other generic services to understand and meet the needs of older people living with HIV.

Other gaps in the existing literature include the specific experiences of women in the UK, and drawing out the impact of immigration on black African women. There are also gaps in understanding the particular experiences of white women (outside of the white heterosexual mixed-gender group) and of women who do not identify as heterosexual (discussions of intimate partnerships, particularly around transmission, assumed male partners in all the included studies where it arose). Receiving social support from others living with HIV through the auspices of HIV organisations and support services emerged frequently. But this opens up

challenges when considered in a context of cuts to services, and changes to service models where service users are expected to cleanly enter and exit a given service within a given timeframe, rather than accessing it indefinitely (Squire 2013). This will be considered in detail in chapter five of this thesis.

One significant gap in the findings of this review was any sense of belonging to a community of people living with HIV which is sustained and operates outside of the functioning of an HIV organisation. While in some cases references were made to making friends in such services that would be seen outside the service, the actual social networks rested within and were sustained by the organisations. This suggests very fragile networks which would be disrupted or even broken by changes or loss of services or organisations.

This review is limited in that it did not adopt a fully systematic approach, and only included qualitative research. The included studies were of good quality, but drawn from diverse settings with very different participant groups, which limited the transferability of their findings and therefore the reliability of the conclusions. They were also conducted within a deficit model, predicated on gaps and challenges, which my research will try to counter. Nevertheless, it sets the groundwork for the wider study, and suggests some directions for the research.

To ensure that women's experiences are reflected and inform each stage of the research, I carried out a participatory analysis of these review findings, in order to draw firmer conclusions.

2.5 Participatory analysis of empirical review findings

The standard research model involves an exploration of the literature, and analysis to surface gaps or under-explored questions, shaping the research questions and design of the subsequent study. In attempting to carry out research that is participatory and adheres to a feminist approach of decentralising the researcher and promoting equality between researcher and participants, I was keen to consider how each step of the research process might be approached differently. Considering the standard model, I concluded that my own

interpretation of the literature and any gaps or questions that emerge from it would be insufficient within the terms of the framework I adopt in my research.

At the core of the feminist approach is a recognition that the research process is not simply objective but is instead necessarily and inherently shaped by the priorities and choices of the individuals and institutions who create research. By exploring the existing literature, you do not just find what previous research has found, but what has been prioritised, what has been sought, and what has been excluded. In the review I conducted of social science research on ageing and HIV, it was clear that research focused on women was largely lacking, as were gender analysis and participatory approaches. The themes emerging from that literature would therefore not be shaped by the participation of women and consideration of gender. To explore the gaps that result from this, I wanted not only to draw on my own analysis, but also to involve older women living with HIV to provide their own insights into what is missing in the evidence base.

I therefore conducted a participatory review. This essentially provided a middle step between the researcher-conducted literature review and the data collection, ensuring that participation underpinned the research project overall.

Participatory approaches involve the people or community being researched in the research process. Typically, this would be in primary data collection, however, it is also possible to build participation into other steps in the research process. I looked for examples of similar approaches being taken, but found nothing. A search for “participatory literature review” on the University of Greenwich library, SAGE journals, Taylor and Francis online, and Oxford Academic Journals databases all returned no results (last searched 1st March 2018). A Google search revealed one relevant result.

This reference to “participatory literature review” was found in a case study, in a report exploring ethical issues in community-based participatory research (Banks and Armstrong 2012). The case study discusses a co-inquiry action research group, which attempted to include community participants in the literature review component of their study. Though this had been identified as an important part of the project, in practice the academics leading this part of the study found it was challenging to do due to limited time and barriers to understanding the process.

Consequently, instead of involving participants in carrying out the literature review itself, the researchers did this first phase, then the results were discussed in meetings with participants.

This mirrors the approach adopted in this study, whereby I conducted the literature review, and the findings from this were brought forward for participatory review. In this way, the interpretative stage of the review was participatory, rather than the search process and initial analysis. This reflects both the restrictions implicit in the study as a PhD, and the realities of the time commitment involved in participation in the earlier phases. However, this does not imply a limitation as such, as participation and experiential knowledge in the interpretative phase responds to the challenge identified in working with a limited evidence base and the priority of including participants in epistemic production.

In order to carry out this review, I approached three women who were acting as community representatives on the PRIME study into menopause and HIV, described earlier in this thesis (PRIME 2015). Their roles in this study suggested they had an existing interest in ageing, women and HIV, and some insight into the research process, as well as connections with other older women living with HIV, which would all be assets in their participation. Two of the women agreed to participate, both women living with HIV. Jane Shepherd is a graphic designer working in the HIV and sexual and reproductive health and rights field. She sits on the Steering Group of UK-CAB (a national HIV treatment advocacy network which informs HIV research) and is a service user representative for her local HIV support services. I know Jane professionally, as she does the graphic design for the ATHENA Initiative, a charity for whom I have also worked. Fiona Pettitt is a member of UK-CAB and a woman living with HIV. I have previously met Fiona at HIV-related events, but we do not know each other well.

The participatory review was conducted through a one-hour discussion, on Skype, which I recorded and transcribed. About a week prior to the call, I shared a summary of the literature review findings and a topic guide for the discussion (Appendix 3 and 4 respectively). Both participants agreed to be recorded, for the discussion to form part of this thesis and to be named. The call took place in August 2016, after the workshops and before the later stages of data collection.

I opened the call with an introduction to the research project and outlined how the discussion would feed into it. The topic guide was followed only loosely, as I preferred for the discussion to flow and to be directed primarily by the participants.

One limitation of the process was that both participants who were able to take part are white, British, and have been living with HIV long-term. This was reflected on during the call, and the discussion frequently noted the need for broader experiences to be included. This was taken forward into later data collection.

Both participants suggested that the overall themes reflected their expectations, but that there were also some gaps. Fiona reflected that 11 articles and reports felt like a small number of research outputs focused on women, ageing and HIV, and was surprised when I shared that in fact many of those included did not solely focus on women. She suggested there may be a gap in the quantity and range of research on this issue:

...but it didn't seem to be very much so I wonder is that a gap? That there's very little research done into women and HIV and ageing. As there has always been I suppose, [on] women and HIV more generally.

Menopause was highlighted as an example of a topic that may be missing from an evidence base that does not focus on women's experiences. The need to include women and ensure their experiences are included was suggested:

... and I suppose the thing is, if there hasn't been many research projects looking at the entirety of women's lives, you're not really going to know where the gaps are until you ask women.

A major theme that emerged in the participatory review was the intersecting, layered experiences that make up women's lives, and how little this can be understood in spaces and discussions that are not shaped by women:

But in my experience... I'm surprised how little other men have any kind of understanding of just simply issues women go through whether they're living with HIV or not, so it does make me think that there, because it's known to us it's not necessarily known to other people at all, around caring for older, you know, parents or children, or having lived a lot of things in your life. Plus, HIV. The intersection of everything is not very well looked at or researched.

The issue of social support and social networks occupied a significant portion of the discussion, particularly the range of experiences and challenges women

might face, and how much broader this is than the narrow view of women reflected in the evidence base. Women who do not have children, women who are geographically distant from their children through migration, or women estranged from their children (as a result of HIV disclosure or other factors) were all identified as women whose experiences are often missed. The issue of not having children was highlighted as particularly relevant to explore, as women diagnosed with HIV may have chosen not to or been discouraged from having children due to the possibility of transmission, particularly those diagnosed before treatment. As well as being perhaps more common amongst women living with HIV, it was suggested that not having children in general is often ignored;

I just wonder if there's an assumption, because you know, women living with HIV, because we're women that we have, that we're going to have family. There's a lot of emphasis on children and your family and I feel like childless women always get neglected.

These different circumstances were all seen as relevant to ageing, and particularly to concerns about ageing with no one to provide care or to assume responsibility if, as a result of age or conditions like dementia, capacity is lost:

... because to me there's a big impact on my future kind of health and you know, if that plays out as dementia, I feel very fearful of how that scenario is going to be without a family to sort of advocate on my behalf.

The potential future need for an advocate to monitor care, or a support network to provide care, was identified as a concern, especially where family was either absent, estranged, or far away. This was exacerbated by concerns around receiving poor or discriminatory care, which is widely reflected in the literature, but often focuses on gay men and expectations or experiences of homophobia. This review emphasised that concerns are also shared by women, particularly about confidentiality, stigmatising treatment and limited knowledge about HIV. One further issue that emerged was that the experience of supporting parents in care could worsen fears, as it provides first-hand experience of how crucial the advocate role can be, and how disempowered the person receiving care can become:

I would be concerned because I've been directly you know looking after my parents and facilitating their care in both a nursing home last year and now a residential care home and I can just see the

vulnerabilities once you're in the care system, in an institution, it's really difficult to negotiate anything for yourself and you really are at the mercy, you know, if you've got nobody keeping an eye on things, you just have to hope that it goes alright.

Providing care to older relatives, especially parents, was a significant topic of discussion. In the UK, women are more likely to be carers, as 58% of unpaid carers, with 1 in 4 women aged 50-64 having caring responsibilities and women having a 50% chance of providing care by the age of 59 (Carers UK 2016). So experiences of providing care are likely to be very common among older women living with HIV. Both participants felt that there were challenges associated with this that did not emerge in the literature review.

Jane described how as parents age, the relationships between them and their adult children change, and can become closer and more intertwined. In her own case, her mother was in residential care, and Jane had a role in managing her care. This had led to the boundaries between their lives diminishing, for example, Jane was connected through social media with her mother's care home, and this presented a significant disclosure issue as her HIV status is visible through that social media. As independent adults, it is possible to construct firm barriers between one's own life and that of one's parents, but if those parents develop care needs this can be harder to maintain:

... because in the past my mother's life was very separate from mine, it wouldn't ever have been, have come up as an issue. So, there's all kinds of unexpected intersections as you get older, which I don't think are taken into account in research at all.

This is not an experience I have come across in the literature but opens up an interesting avenue for exploration: how relationships change as people age, and how family relationships in particular alter with time. The issue of shifting dynamics in the relationship between people living with HIV and adult children is represented in the literature (Murphy, Roberts et al. 2012, Rosenfeld, Anderson et al. 2015). But changes in the relationship between people living with HIV and their parents, as their parents reach old age, is not so explored. For both participants in this stage of the research, this was an important, defining experience in their own lives and for women they knew.

Additionally, the discussion highlighted issues that are present in the existing literature that were felt to be important, including the impact of disclosure on accessing effective social support. The participants did feel that being unable or unwilling to disclose HIV status could be a barrier to receiving social support, as this secrecy can create distance:

It's just that I think disclosure becomes an issue with support in that it reduces your kind of ability, it can reduce your ability to get close to family members, to keep the kind of distance, which could be a barrier to asking for support.

In addition, they described the negative experiences of other women they knew who have either disclosed or had their HIV status revealed and experienced stigmatising responses from family members, entirely excluding them as sources of support. These experiences affected a number of women directly and could also impact on the disclosure choices of others who heard about them.

In relation to intimate partners, as well as the barriers posed by disclosure, which emerged in the literature, a new theme Jane and Fiona suggested was the challenge of finding a partner when standard routes are unavailable, such as dating sites (which may also be less accessible for older people with lower levels of internet literacy):

... you might feel a disadvantage because you can't, you know, to use dating sites and things, because there's a real issue once you're diagnosed with HIV, I think it's quite, it's a barrier to using those methods.

Or meeting a partner through friends:

... like generally friends may introduce you to people who they think would be a good partner for you, and I wonder whether sometimes, it would be interesting to know whether if you're HIV positive, whether those introductions take place less.

Productive social connections link individuals to practical support, emotional support, and to opportunities such as jobs, friends or intimate partners. Here, it is suggested that for people living with HIV it is not just the support that might be missing or diminished, but the function of a social connection in opening up new connections. In a social network, it may be that connections are 'shut down' by HIV, so prevented from connecting to additional contacts. This has suggested a

new avenue to explore around social networks and how they function for people living with HIV.

Ageism was also identified as an interesting area for further study, particularly regarding whether women living with HIV and women without HIV had different experiences. Fiona suggested on the one hand that ageism would be a common experience for all women:

... because my suspicion is as you get older, you hear about women for example becoming invisible, or I don't know, but there's you know sort of less respect maybe as you grow older.

But that HIV stigma may also worsen with older age:

... I mean I'd imagine if there is, if people experience stigma then I could imagine it would, that it's from being HIV positive, then I don't see it dying away, as they get older and I don't know, I don't know whether it might get worse, whether you know, perceptions of how you may have become HIV positive, if you disclose to people who aren't particularly close to you, they would perceive you in a different way to how they had perceived you before...

This issue is an interesting area to explore further with specific reference to the gendered experience of ageing that Fiona highlights and Jane described further:

I could imagine maybe that maybe there's again an intersection between how women's bodies and attractiveness and desirability is perceived with age generally and then also that you've got a layer maybe of self-stigma and lack of confidence about your, you know, your sexuality and your ability to have pleasure and sex and, so those two things might kind of compound each other.

The physical effects of ageing with HIV, including visible issues like lipodystrophy, were also highlighted as relevant to understanding these experiences.

With respect to comorbidities and additional conditions, it was suggested that dementia was largely missing from the review but warranted inclusion. This was linked to care needs and particularly the need for support managing medications. This was also reflected in the literature, but one additional layer that emerged in the participatory literature review was the issue of treatment options. For some people living with long-term HIV who have had treatment challenges, there may be an even higher priority on good adherence, as they have few or even no other treatment combinations available due to resistance. In these cases, diminishing capacity leading to poor adherence could have huge health consequences.

The discussion also highlighted the different experiences and priorities of those long-term diagnosed compared to more recently diagnosed women. While this disaggregation was present in some studies, there is scope for more comparative analysis in many cases, which draws out the differences in more detail.

The issue of peer support and HIV support services was also discussed. Jane described how in low or medium prevalence areas, it could be difficult to provide tailored support services for older people, and to find people to attend them, especially if it involved engaging with external, non-HIV agencies which people may be reluctant to do due to disclosure concerns. Fiona suggested that more research would be useful to explore the support needs women have and their preferences for services to meet them. Jane also described how mixed groups could be challenging:

... in my group which is very mixed, it's always, the conversations always gravitate towards gay men's needs, we're always talking about gay men's issues. I don't even, I don't even think, they don't even register I think that I'm a woman so I might have different experiences. And I really couldn't bring anything that's troubling me to the support group, because I just, I just wouldn't want to be, I wouldn't want to be dismissed or silenced, or not heard, or, I'd rather just not bring it up.

I found this part of the discussion particularly interesting, both in what was vocalised in terms of the unintended silencing of women in mixed settings, and the unsaid, specifically the emotional labour involved in attending a support group where one's own needs are not recognised or discussed. Research on peer support generally assumes that participants are engaged in both giving and receiving support. Jane's comments suggest that this may be an inequitable exchange.

The theme of uncertainty emerged very strongly in the literature, and also resonated for Jane and Fiona. This reflects ageing itself, and particularly the menopause as a period of transition, that involves significant change and associated uncertainty. This included difficulty in attributing symptoms to HIV, age, treatment side effects or other health issues:

I think that was something that came out through the PRIME study that it was difficult to know what's causing what and I think that looking at myself, and especially because I've been a long-term

survivor who experienced quite a lot of health issues back in the nineties, it does, you know, sometimes I, sort of worry about whether it's HIV-related or not, and sometimes it's not, or a lot of times it probably isn't, but it is complicated looking at what's what.

The emotional and psychological impact of uncertainty was linked to the experience of having lived with a serious and life-threatening condition (when diagnosed prior to effective treatment) and the long-term attritional effect of living with concern about your health.

As a researcher, I found the participatory review process very useful. In some areas, it reinforced my own analysis, which I found bolstered my confidence and interest in pursuing those issues. Other issues emerged which I had not considered, particularly around women who do not have children and the different functions of social networks for people living with HIV. I was aware in the conversation that I behaved differently to how I generally enact my role as researcher, in that I was more involved, and more personally expressive in my own views. This was, I think, a function of my knowing the participants and meeting them on an equal footing in this discussion: they were not sharing their experiences as such but responding to the literature, just as I was, but from a viewpoint informed by lived experiences that I do not have. The balance was therefore quite different to a standard research interaction. In transcribing the call I was careful to listen for any point where my own views may have influenced the conversation, but overall am confident that my contributions were reactive rather than directive, expressing agreement with what Jane or Fiona had already said. Where I asked questions or identified issues, I did so with a neutral tone.

Reading the transcript, one element which particularly struck me was the sense both participants conveyed of being or feeling like a minority as women among people living with HIV. Within medical research and more broadly in interactions with the medical profession and institutions, women can be seen as a minority in that the male body and experience of illness is treated as the norm, with women the deviation (Mazure and Jones 2015). For women living with HIV in the UK, this is even more the case, as the masculine norm exists in HIV care and services not just as a function of patriarchy but as a product of percentages. In the UK, most people living with HIV are men, women are 29% of the population of people living with HIV (Public Health England 2018) . This participatory review

highlighted how this impacts women's interactions with medical care, services and peer support, and can serve to systematically invisibilise women's experiences, but that this can be easily missed not just by others, but by women themselves.

The participatory review shaped the issues and questions taken forward to later phases of this study.

2.6 Literature review update

The original review was conducted in March 2016, about 15 months into this research study. The participatory review was carried out on the literature reviewed at that time, and so the preceding sections reflect that time boundary. Here, I present a brief overview of new research and other developments published after the initial review was carried out, until February 2019 when this update was undertaken.

I re-ran the original search, using the same methodology. After applying the inclusion criteria and screening abstracts, four relevant studies were included. Four additional articles were identified through hand searches, and judged to be relevant and of good quality, according to the original inclusion and appraisal criteria. Of the eight included studies, seven are from the US, suggesting there has been an uptick in research on women living with HIV in the US, but that this is not replicated elsewhere. As previously acknowledged, the context of healthcare and the HIV epidemic in the US is quite dissimilar to the UK situation, so generalisability from these studies is limited. The other study is from Canada, a more similar system but with important differences.

One study focuses on challenges with managing complex health needs, accessing care and adhering to treatment, in the context of the rural US (Quinn, Sanders et al. 2017). The study found that managing multiple co-morbidities caused challenges and uncertainty, and that this, alongside financial and geographical barriers, stigma and fear of stigma, caused problems with adherence.

A study conducted in the US with a large sample of older women living with HIV explored sexual health and wellbeing (Taylor, Munoz-Plaza et al. 2017). The authors found that sexual pleasure increased with age for many participants, as they grew in confidence and self-awareness, the desire to maintain intimacy and sexual pleasure in older age was important. Menopause and moving beyond social expectations for women to procreate increased sexual freedom for some women, but physical changes such as post-menopausal vaginal dryness, changes in desire and decreased mobility could limit sexual freedom and pleasure.

The other studies predominantly focus on social support, resilience, and ageing well with HIV. A study with a clinic-based sample of older people living with HIV found that receiving more social support can enable more effective coping with HIV and support resilience (Kapadia, Levy et al. 2017).

Another study explored social support in the context of self-management (Warren-Jeanpiere, Dillaway et al. 2017). The study found four themes defining women's coping and views on social support. The first, 'Life begins at 60', describes participants' sense that older age was accompanied by greater self-acceptance and acceptance of HIV status, more positive outlook and self-image, and a greater sense of what was important. The second, 'Stop worrying about everybody else' encompassed a sense that instrumental and emotional support was essential to improved self-management and self-esteem, and that achieving this meant putting their own needs first, and seeking to reduce the burden of supporting others, including in some cases a desire for formal HIV-related support for family members.

Thirdly, 'the silence is killing us' describes the need for emotional support to deal with HIV-related stigma, that is informed, non-judgemental, empathetic and potentially provided by peers. Finally, 'I need something more' captures changing and increasing emotional and instrumental support needs with increasing age, and favoured sources of support shift to peer support (from other older women living with HIV) and mental health therapists and healthcare professionals (Warren-Jeanpiere, Dillaway et al. 2017).

Similar themes emerged in a study with older African American women living with HIV, which used a feminist approach to explore resilience and how women coped with health challenges (Subramaniam, Camacho et al. 2016). All participants in the study had low economic status and two or more co-morbidities in addition to HIV. Four themes of resilience emerged: self-acceptance, optimism, support systems and religion and spirituality. Self-acceptance is described as a process of moving beyond stigma and shame experienced at diagnosis, to acceptance of HIV. Optimism included feelings of gratitude, positivity, and looking ahead with aspirations. Family and friends and HIV organisations provided vital support, but intimate partnerships were often fragile, and faith was a source of hope and strength for many participants.

Another study, conducted in Canada, explored women's experiences ageing with HIV with a focus on episodic disability and rehabilitation, specifically occupational therapy (Akhtar, Garcha et al. 2018). Women described varying levels of acceptance of HIV, influenced by perceptions of long-term treatment, and HIV as a long-term condition. Stigma was a concern, and limited or influenced disclosure, and impacted family relationships and intimate partnerships. Women described experiencing declines in both physical and cognitive functioning, which impacted their lives and could be a barrier to employment. For many, ageing with HIV involved living with negative emotions, including worries about the future, isolation and sadness. Emotional support from family, friends, support groups and counsellors were used to help healthy coping, as was support from community services. Social connections with other women living with HIV and through groups were valued.

A study with black women living with HIV in the US found that stigma linked to race, gender and HIV status manifested at different levels, through negative stereotypes and discriminatory behaviours (Sangaramoorthy, Jamison et al. 2017). At the family and interpersonal level, this included gender-based violence, control, and coercion, as well as impacting on the performance of gender roles and associated concerns such as enforced childlessness or challenges in fulfilling the expectations of the role of mother, daughter, partner or sister. At the broader community level, stigma manifests as silence and discrimination, while at the institutional or structural level women described discrimination in the work place,

healthcare settings and social service settings. The authors found that stigma is persistent in women's experiences over time, but that women described being better able to cope with it as they grew older.

A similar process of ageing leading to growing resilience and greater ability to manage living with HIV and associated challenges was found in a study with 19 women in Boston, which reviewed women's experiences of coping with HIV over time (Psaros, Barinas et al. 2015). The study revealed three major themes: experiences of diagnosis, and subsequent move from fear to acceptance as time passed; the uncertainty over HIV itself and how it would progress, complicated for some women by limited treatment options, and other health problems; and, the process of acceptance over time, associated with a positive change in personal perceptions around having HIV, greater sense of perspective, and the sense of having survived for longer than anticipated.

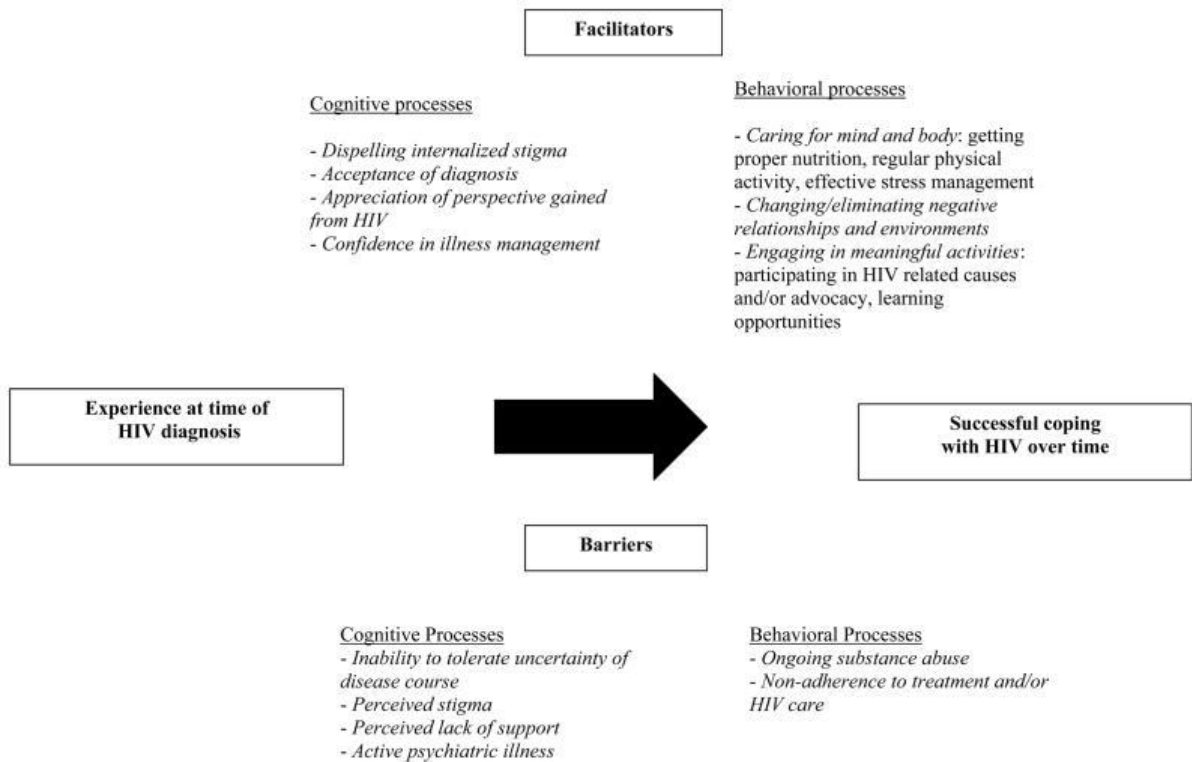
Psaros, Barinas et al. (2015) further identified three sub-themes, of strategies to support living successfully with HIV over time, which they developed into a model, shown at Figure 2.1. This model is used in chapter nine to guide analysis of data from my study. It considers cognitive and behavioural processes that facilitate or inhibit successful coping with HIV over time. The processes identified by Psaros, Barinas et al. (2015) reflect many of the articles included in this literature review update, particularly accepting HIV status, managing health and wellbeing, accessing support and finding a sense of purpose.

Two further studies, in grey literature, were also published in this period, both in the UK. THT conducted a new study on ageing, building on *50 Plus. Uncharted Territory* explores the experiences of older people living with HIV in the UK, using a peer researcher model (THT 2017).³ The report acknowledges that the population of older people living with HIV is internally diverse, with differences in age, socioeconomic status, health and other factors (THT 2017). In particular, differences were found between people diagnosed before and after effective treatment became available, with the former group less likely to be employed and

³ I communicated with the lead researcher on this project, sharing insights from my own research, and reviewed the report prior to publication. THT also shared raw data with me from focus groups and the survey, which I reviewed, and was very helpful in illuminating similar themes and issues that arose in my own qualitative data.

more likely to be reliant on state benefits, as well as being more likely to have three or more health problems in addition to HIV. For participants aged between 50 and 60, work and benefits were major concerns, while those aged 65 and over reported higher levels of wellbeing.

Figure 2.1: Facilitators and barriers to coping with HIV over time (Psaros, Barinas et al. 2015)



Uncharted Territory includes a section on women, a progression from the *50 Plus* report. It found that women reported lower levels of wellbeing and lower incomes, compared to men (THT 2017). Overall, women reported higher levels of concern than men about all aspects of ageing with HIV explored in the study, suggesting a much greater level of need for support and information.

Another UK study explored experiences of stigma, and how these change as people age (Nagington, Hutchinson et al. 2017). Participants described feeling they had “different faces” they used in situations with different people, depending on their expected level of knowledge and stigma about HIV, which could create feelings of isolation and separation from friends and family.

2.7 Conclusions

In seeking to understand how women in London are living and ageing with HIV, I have been guided by the existing literature, and more so by the gaps within it, as identified through the participatory literature review. The internal heterogeneity of the older population of people living with HIV, and the differing experiences of women who do or do not have children, or of different sexualities, gender identities, ethnicities or migration experiences, and across different treatment eras or ages, have all recurred in the literature and guided the recruitment for and analysis of my own primary research.

In the period since the initial review was conducted, there has been an increase in the available evidence on ageing with HIV, though much of this is from the US, and so there remains significant gaps in understanding women's experiences in the UK. Much of the available literature focuses on need, which I aim to move beyond to explore both positive and negative aspects of women's experiences of ageing with HIV.

3. THEORY

In this chapter, I present a discussion of the key concepts underpinning my research: community and participation. Building on this, I outline the theoretical framework for my research.

The concepts of community, participation, and linked to both, advocacy, are fundamental to both understanding the history of HIV research, and conducting such research. HIV is not just a health issue, but a social phenomenon, in both who it affects, and how they are affected (Mann 1999, p.201):

With the passage of time, and as the epidemic matures, it evolves and moves along a clear and consistent pathway, which, although different in its details within each society, nevertheless has a single, vital, common feature. In each society, those people who before HIV/AIDS arrived were marginalised, stigmatised, and discriminated against become over time those at highest risk of HIV infection.

Terrence Higgins Trust, a UK HIV charity, has a phrase it often uses in social media and publications: “HIV does not discriminate”. Clearly a rhetorical device, the phrase comes in and out of favour, depending on whether the prevailing advocacy winds are directed towards recognising the most affected, or promoting the message that anyone can be affected. But while the virus itself does not create discrimination (stigma, misogyny, racism and homophobia are the primary causes of that) it is not accurate to suggest that everyone is equally vulnerable to HIV. The quote above is from Jonathan Mann, an American doctor and campaigner who was a key figure in the early AIDS response, who argued passionately for the links between HIV and human rights. As he suggests, in any society, it is the communities already marginalised who bear the brunt of HIV. In the Global North, gay men, people who use drugs and migrants face the greatest impact and are also often least able to challenge the stigma, discrimination and rights abuses that too often accompany HIV.

It is also the case, however, that as the global HIV pandemic has endured, communities have mobilised to claim their rights and respond to HIV. The extent and impact of this mobilisation is not always clear, as the forces of governments, pharmaceuticals and other actors are also in play. Nonetheless it is increasingly recognised that the HIV response has been to some extent shaped by advocacy, and that HIV advocacy as a phenomenon exhibits unusual characteristics

compared to other health conditions, such as the central involvement of ‘patients’, and the engagement with science leading to scientific progress (compare the progress in HIV treatment to TB or malaria treatment, to see the impact of this in action). UNAIDS, in their report, *How AIDS Changed Everything*, suggest lessons that the HIV response proposed for the wider development community, including advocacy (UNAIDS 2015, p.174):

In the beginning, there was advocacy. Before there was a name for the disease, before the money, before the institutions, there was a movement of people who demanded answers, resources and a voice. Public health officials had never faced such a strategy. Early AIDS advocates applied political activism tactics. They made health a human right. They also made it their business to understand the science behind the disease even as researchers were learning about it themselves. This combination made for a powerful advocacy platform.

The history of the community response to HIV is only partly written. The films, plays, and other media that tell the story of HIV often reflect the experiences of gay men in the Western world. There are comparatively few accounts of women’s organising and collectivising to respond to HIV.

In the following sections, I explore the literature on community and participation in the context of HIV, in order to consider how and whether communities of women living with HIV form and function, what involvement in such community involves and offers, and how other forms of participation have emerged for women living with HIV.

3.1 Community

In a former job, I worked closely with Ffena, a UK-wide activist network of African people living with HIV. One older woman member had a stroke, and lost mobility in one side of her body, leading her to move into local authority-funded residential care. There, she encountered discrimination: unable to feed or wash herself, staff refused to provide this basic care due to stigma about her HIV status. This story might seem to confirm the fears reported by older people living with HIV about discrimination in residential care (Power, Bell et al. 2010). But she was visited by another woman living with HIV from her community, who saw what she was experiencing and decided to act. She mobilised the community, and a group of women living with HIV came to the care home, protested outside, asked to meet

the manager, shared information about HIV and demanded change, which they secured. This story for me illustrates the enduring power of community and advocacy forged in shared experiences of HIV, as well as suggesting the potential for communities themselves to resolve some of the issues associated with ageing with HIV.

Community, in this example, provided practical and emotional support, a safety net and supporter network. Community can take many forms, as here, where communities of women, African people, and people living with HIV overlapped, with members perhaps identifying by or motivated by each of these shared identities, but to different degrees. In this study, I have sought to explore and understand what communities women living with HIV feel part of and what secures or motivates that belonging.

‘Community’ as a concept captures this feeling of belonging. The sense of a ‘community of people living with HIV’ has emerged since the onset of the epidemic and coalesced into various forms. In the western world, it is perhaps most strongly associated with gay men – the first to be identified with HIV and AIDS, and where the ‘gay community’ and ‘HIV community’ overlapped and, to some extent, integrated (Fowler 2014, ICW 2015, UNAIDS 2015). There is a significant body of literature exploring gay communities in the context of HIV, but much less that explores communities of women living with HIV. Nonetheless, through peer support and other networks, the manifestation of community is evident through the history of women and HIV and continues to be constituted and re-constituted, through actors and actions including research such as this. I will firstly review the literature on the concept of community and how it emerges in relation to HIV, and then explore the roles of advocacy and intimacy in creating and sustaining communities.

The term ‘community’ is contested. Multiple, sometimes conflicting, definitions occur, in academic and regular use, making it difficult to define (Cohen 1985, Amit 2002). Yet the reality of it being so often used, and the proliferation of definitions attached to it, suggests that the concept has some impact and poignancy, and so it remains useful (Amit 2002). That the concept is contested

does not undermine its value, in fact the debate is helpful in illuminating the potential for community, its opportunities and challenges (Crow and Mah 2012).

'Community' can be defined through the usage of the term, Cohen (1985) argues, a reasonable understanding of which suggests that 'community' implies a group of people that share something in common, which distinguishes them from others, such that the term itself is relational including both internal similarity and external difference. This sense of difference is defined by Cohen as the 'boundary', which delineates the community and defines what is within and what is outside. This boundary is necessary because it defines the identity of the community in relation to others with whom members of the community must interact. The nature of the boundary is determined by the nature of the community and is often simply perceived and defined by members, and the meanings they assign to it.

Community therefore encapsulates the human experience – the social interaction and support that people need, as well as an inclination to create barriers and delineate who is inside and who is outside, as we cannot support or share with everyone (Day 2006). Community can be used positively, to describe or imply connection and support, or negatively, in its connotations of exclusion, inequality and division (Crow and Mah 2012).

Based on a review of research published since 2000, exploring the concept of 'community' and how it is operationalised, supplemented by interviews with researchers, Crow and Mah (2012) developed four linked and overlapping themes to describe the theoretical, empirical and methodological exploration and development of 'community'. These four themes are: connection; difference; boundaries; and, development. These apply to all forms of community, including those formed around place, identity and other factors. Connection refers to how communities form and are maintained. Difference includes both difference within and between communities and others outside the community. Boundaries include multiple forms, linked to the first two themes as well to issues of place and mobility. Finally, development captures the contested notion of 'community development' i.e. how a community progresses or improves in key areas such as crime, health or wellbeing (Crow and Mah 2012).

While scholarly work has not produced a precise definition of the term 'community', attempts to produce one have coalesced around a set of key questions, focusing on the impact of a shift in modern social structures (such as globalisation) on social solidarity and affiliation (Amit 2002). The perceived tension between modern, individualised, globalised societies and community is not uncontested. Cohen (1985) argued that the suggestion of a necessary tension between globalised modernity on the one hand and the persistence of community on the other, is undermined by evidence of growing community consciousness, such as the emergence of class, ethnicity and localism as effective concepts for community organising. Others suggest that a desire for intimacy and community belonging are effective in maintaining solidarity and sustaining communities (Wilkinson, Bittman et al. 2012).

Amit (2002) identifies a shift from community perceived as actualised and physical, to community as an idea formed through shared identity as opposed to social relations. In this way, community became defined not in relation to place but "it had become the nexus of an inextricable convergence between culture, place, intricate social relations and collective identity" (Amit 2002, p.5). In urban contexts, cities and the communities within them have been described as living things, created, produced and determined by the people within them and the relations they form (Castells 1983).

Community then can be seen to be formed through ideas and shared identity, and defined by connection, difference, boundaries and development. It can be linked to place, or shared characteristics. While the form of community changes, and is changed by global and social processes, it persists as both a 'real-life concept' and a methodological and sociological unit of exploration.

There is further debate over how communities are constructed, and sustained. In a seminal text on the concept of community, Benedict Anderson explored nationalism, in the context of rising nationalist conflicts and self-determination claims (Anderson 2006). He defined a 'nation' as an "imagined political community" (Anderson 2006, p.6). Anderson suggested that all communities beyond the smallest face-to-face grouping are imagined (Anderson 2006, p.6):

It is *imagined* because the members of even the smallest nation will never know most of their fellow-members, meet them, or even hear of them, yet in the minds of each lives the image of their communion.

This decoupling of real relations and community that Anderson outlined is further supported by the proliferation of print media, through which it became possible to 'imagine community' – to experience social solidarity and belonging based on shared ideas rather than shared place (Amit 2002). That is, to experience a sense of community with people with whom there is no 'real-life' interaction. As Amit notes, this possibility has been opened up further by electronic media. The concept of 'imagined communities' has been criticised for lacking a grounding in reality and lived experience, and hence he suggests the concept must be modified (Amit 2002, p.8):

If communities must be imagined, then by the same token, what is imagined can only be truly felt and claimed by its potential members if they are able to realize it socially, in their relations and familiarity with some, if not every other constituent. To treat the idea and actualization of community as if these are in essence independent elements is to leave us and our analyses with only one hand clapping.

This is realised through a broad sense of belonging to a community that can be large, diverse and predicated on only a few shared experiences or characteristics, which is mediated through actual social relations and face-to-face interactions with some members of that community, giving reality to the idea. Though this role of the social in the imagined is debated, and was rejected by many scholars, Amit (2002) suggests that embracing just the imagined aspect of community risks cultural determinism, characterising people as being without individual agency to influence how community is enacted. He therefore calls for us to "re-embed community in a social as well as conceptual context" (Amit 2002, p.10) – this is, I would argue, a more convincing approach.

Amit (2002) contends that community is formed and has meaning and affect where there is both an 'imagined community' built out of shared identity and ideas, and where it is enacted by people because of and through actual social interactions with others they associate with that community. Community in this sense is contingent, fragile and flexible, one of multiple possible options rather than all-encompassing. The role of the imagined and the actual, and the individual

agency this conception of community allows, is broadened in the concept of 'personal communities'. This is based on the recognition that each individual is the star of their own world, they experience life in the centre of a web of contacts, positive and negative: 'personal communities', built of individual connections, sources of support and cross-connections (Chua, Madej et al. 2011).

Chua, Madej et al. (2011) develop this concept of personal communities, identifying three ways of understanding community: local or neighbourhood communities based on place; communities of interest; and the less traditional understanding of personal communities, defined by the individual at the centre. These personal communities include relations both on and offline and may include people physically nearby or very far away. The form of these communities has been dramatically altered by social and other media, and the increase in modes of connection and communication available. Shifting social norms have, Chua, Madej et al. (2011) suggest, led some commentators to diagnose a decline in community and social interaction, yet instead it seems that informal connections and new forms of community have arisen, maintaining the central role that personal community plays in individual lives. It is the nature of social interaction that has changed, moving from face-to-face contact to social connection through the internet, possibly across great distances.

The personal community approach views 'community' from the individual to their connections, rather than a community as a whole. The ties to others within the personal community can be weak or strong, and involve social interactions of various sorts, including family, partners, friends, colleagues and others (Chua, Madej et al. 2011). Personal communities are often geographically dispersed, including both local and global contacts (Chua, Madej et al. 2011). The network of the personal community is also often sparsely knit, with few ties between others in the network. The links within the network are often specialised, with particular types of support being exchanged on a reciprocal basis between the individual and their social contacts. Further, they suggest that personal communities often reflect similarities in terms of features such as race, class, or interests. As a result of personal communities, individuals benefit from social support, differing in kind between different kinds of connections, including family and friends and including advice, information, emotional support and resources (Chua, Madej et al. 2011).

The nature and structure of personal communities changes with age and circumstances, for example as older people retire and co-workers are removed from their personal community, the role of and support sought from family may change (Chua, Madej et al. 2011). The personal community also contains both family and friends, with attendant social expectations and behaviours associated with the two categories (Pahl and Spencer 2010). The roles of family and friends have different expectations attached to them, such that family may be described as more important even where friends actually provide more support, as the ideal and reality differ (Pahl and Spencer 2010).

Personal communities can take different forms, and be more or less robust, depending on features such as the level of redundancy or connection within the community. This model allows for modern changes such as an increase in friend-based and chosen rather than given personal relationships, and a decrease in the centrality of the family unit. This does not, however, suggest that personal communities are more individualised or selfishly-motivated: “We must make it emphatically clear that we reject the idea that greater choice necessarily implies less commitment” (Pahl and Spencer 2010, p.206). This is particularly apposite to consider in relation to individuals who may lack or have lost family ties, in the HIV context, due to the impact of stigma, migration or ill health. Communities of choice are not necessarily weaker than given or family communities.

Similarly, Roseneil and Budgeon (2004) argue that in the 21st century, with changing forces of individualisation and cultural and social change, the family should not be understood as the central unit of intimacy and care, and researchers should instead look beyond the family to partners and friends. In particular, they highlight how the sociological focus on family exists within heteronormative and gendered frameworks. Their work highlights the need to expand research to include new forms of intimacy, in particular to adults living without a partner who demonstrate models of intimacy characterised by the centralisation of friendship and decentralisation of sexual relationships (Roseneil and Budgeon 2004).

The need to recognise families of choice and the role of friendship in providing social support, intimacy, and community is particularly clear in relation to HIV,

where family may be absent, and the impact of stigma leads people to form or enter communities of shared HIV status to find support that is knowledgeable and non-judgmental. A shared, global, experience of HIV has created a space for 'imagined communities' crossing borders, and an international sense of community and belonging for people living with HIV. The proliferation of new media and increasing access to it has opened up channels to make this sense of community affective – to join with and form social links with others sharing facets of identity or experience without ever physically meeting.

The term 'community' is frequently used in reference to HIV, where communities are defined both by risk of HIV and by living with HIV. The application of community and community participation to health, including HIV, has a long but contested history (Mayo 2000). The role of community in promoting health, in disease prevention and in defining health as a shared public good have all been key features. The focus on community in health has been seen as an alternative model to medicalisation and attendant categorisation of social outcomes as health problems (Mayo 2000). Community strategies to promote health recognise that provision of information is insufficient on its own to change behaviour, where challenges in access and opportunities to implement behaviour change persist (for example, women who lack the power to negotiate condom use need more than simply to be informed that condoms are effective) (Mayo 2000). Instead, in relation to HIV, community health approaches must address the social, cultural and economic factors that prevent people from practising safer sex (Mayo 2000). The extent to which 'community' offers an alternative to or is part of medicalisation and biomedicalisation in the experiences of women living with HIV is explored in this thesis.

The application of community in relation to HIV has also led to an application of 'sexual community', with expectations of action motivated by community belonging amongst, particularly, gay men living with HIV in relation to prevention specifically (Davis 2007). This demonstrates different uses of the concept applicable to different groups, and the multiple forms community can take.

The overwhelming majority of research around community and HIV focuses on gay men, and there is little available literature on community, women and HIV.

This review suggests many questions to explore. What does it mean to belong to a community? How does one choose from multiple options, or co-exist within and between multiple communities? What social, political, or governmental functions does 'community' serve for women living with HIV?

In addition, in the context of HIV there exists two 'types' of community. The first is centred on formal structures, formed through peer support, networks or organisations, with an underlying formality based on funding, leadership and defined entry mechanisms. The second is personal communities of people living with HIV, who create their own networks including friends and contacts also living with HIV or otherwise connected to their HIV identities. These personal communities may be entirely merged with the larger personal community of the individual, or operate quite separately, depending on disclosure. Anecdotally, it is my experience that it is not uncommon for people living with HIV to have two distinct personal communities, one HIV-related and one not, with the former aware of but kept separate from the latter, and the latter, thanks to non-disclosure, kept deliberately uninformed about the existence of the former. I am interested to explore how older women living with HIV define and manage their personal communities, and the role of HIV within them. I also seek to understand the role of formalised HIV-related communities, what role these play, how they overlap or intersect with personal communities, and whether they are valued by older women living with HIV. This is particularly interesting in the context of ongoing cuts to HIV services, and a drive, as Squire (2013) described, towards self-help and time limited service interactions, potentially ending the space of support groups as a permanent fixture in individual social networks.

I further seek to understand the function that communities, in various forms, serve in the lives of these women, and how in practice community and belonging is mobilised. In particular, what roles or behaviours communities might mandate or impose upon women who belong to them, and what advantages they might confer. These considerations are explored in chapter eight of this thesis.

The history of community in the context of HIV and women is also important to review. In the early days, the impact on individuals affected by HIV was almost unimaginable. Fear, a lack of knowledge about or any treatment for HIV, stigma

and discrimination, and loss of friends and loved ones shaped the communities that formed in the face of it. A defining feature of these communities was advocacy – for treatment, for information, for the rights of those affected. For women, the early HIV response was often blind to the impact of HIV on them and their specific needs. In 1991, women living with HIV attending an international meeting of the Global Network of people living with HIV (GNP+) found that the meeting largely included and focused on the needs of men, leading them to establish their own network, the International Community of Women living with HIV (ICW 2015, no page number):

Women were left out of all the discussions. They were excluded from the decision making processes and not given space at local, regional and especially not international levels. Each one of the women who went to the meeting in London had their stories to tell, their own questions, their fears and so many uncertainties in relation to their experiences. Many of them came from different countries; spoke different languages, belonged to different cultures. But despite this nothing prevented them from understanding one another and their exclusion they felt from the HIV movement. It was at this meeting that the women decided that things needed to change and that they needed to mobilize. This was the first time in the history that a group of women got together and used a gender perspective to challenge patriarchy and discuss their experience with HIV.

This language clearly sets out the political aims of the establishment of ICW and the sense of exclusion that drove it, the hyperbole evident in the description resonates with the language often used by activists to gain attention and signal the importance of their cause. ICW formally launched at the International AIDS Conference in Amsterdam in 1992. Since then, it has worked at local, regional and global levels to establish support networks, conduct research, influence policy and programming, and advocate for the rights of women living with HIV. The connection between community and advocacy has been intricate and ongoing, with the activities of ICW fuelled by a dual motivation: to establish and sustain community and to use this to advocate for the rights of that community.

The foundation of ICW is a set of 12 statements formulated in their first meeting, shown in Figure 3.1 below (ICW 2015). In addition, the first ICW members developed a toolkit, the 'Positive Women's Survival Kit' as a resource for women newly diagnosed and living with HIV (ICW 1999). The kit contained guidance on

dealing with diagnosis, staying healthy, relationships, sex and sexuality, and pregnancy and childbirth, and other topics. Written by women living with HIV, it features many quotes sharing personal experiences and insights. This form of advocacy, using personal experiences to support others, is perhaps the defining feature of women's advocacy in response to HIV. The kit encourages women to know and understand their rights, and to take control of their journey with HIV by being informed with both facts and the experiences of others.

Figure 3.1: 12 Statements (ICW 2015)

1. WE NEED encouragement and support for the development of self-help groups and networks.
2. WE NEED the media to portray us realistically and not stigmatise us.
3. WE NEED accessible and affordable healthcare (conventional and complementary) and research into how the virus affects women.
4. WE NEED funding for services to lessen our isolation and meet our needs. All funds directed to us need to be supervised to make sure we get it.
5. WE NEED the right to be respected and supported in our choices about reproduction. This includes the right to have children and the right not to have children.
6. WE NEED recognition of the right of our children and orphans to be cared for and of the importance of our role as parents.
7. WE NEED education and training of healthcare providers and the community at large about women's risk and our needs. Up-to-date, accurate information concerning all issues about women living with HIV/AIDS should be easily and freely available.
8. WE NEED recognition of the fundamental human rights of all women living with HIV/AIDS, particularly women in prisons, drug users and sex workers. These fundamental rights should include the right to housing, employment and travel without restrictions.
9. WE NEED research into female infectivity, including woman to woman transmission, recognition of and support for lesbians living with HIV/AIDS.
10. WE NEED decision making power and consultation on all levels of policy and programmes affecting us.
11. WE NEED economic support for women living with HIV/AIDS in developing countries to enable them to be self-sufficient and independent.
12. WE NEED any definition of AIDS to include symptoms and clinical manifestations specific to women.

Similar networks and communities emerged regionally and nationally, from European and Pan-African networks to national and local peer support and advocacy networks. In the UK, Positively Women formed in 1987, established by two women living with HIV who found there were no services available for women (Positively UK 2015). Modelled on peer support, the charity established a range of services and advocacy activities delivered by and for women living with HIV.

The recent history of Positively Women is also instructive of a broader shift in the needs and activities of communities of women living with HIV. The charity has now renamed as Positively UK and offers services to everyone affected by HIV including gay and heterosexual men. Since the emergence of effective anti-retroviral treatment in the late 1990s, HIV has shifted from a life-threatening condition to one with which people can live long, healthy lives. The women that established ICW and Positively Women did so in a context of fear, isolation and the unknown. Many people were dying. In the toolkit mentioned above, sections are devoted to 'memory books' and preparing for death with wills and practical plans, and to 'grief and loss' (ICW 1999, p.38):

Some of us have already lost our parents, children, partners, siblings, children [sic], friends and colleagues through HIV. We carry a heavy burden of sadness and grief. Losing other positive women we have joined with for support and to fight for our rights, brings another level of sadness to our lives.

Women diagnosed in the 1980s and early 1990s tell stories of many losses, funerals, attending peer support groups and wondering who would still be there at each meeting. This created an urgency and fierce loyalty and determination in those early days of forming communities and advocacy networks. Women were fighting for their lives. Now, the picture is very different. For women in the UK, treatment is effective, available and accessible, and most women living with HIV can expect a near-normal life expectancy. This has changed the way communities form and sustain, and the role of advocacy within them. These changes are explored through the life stories of women interviewed for this study.

The experience of being a woman living with HIV now is very different to earlier parts of the epidemic. For women who were diagnosed in that earlier period, fear of dying was present and then dissipated, but many others, friends and colleagues, were lost. In the workshops and life story interviews, I explored how this has shaped women's advocacy, sense of community, and their motivations and experiences.

I also explored how communities of women living with HIV co-exist with other communities, including communities of people living with HIV, and personal communities of family and friends. I have described here the global, regional and national networks of women living with HIV, but there are other networks that are

not gender-specific. Some women find their sense of belonging and source of support within mixed gender groups or settings, and these preferences are explored in the findings chapters also.

How community is sustained is also important to consider. With the advent of treatment the ferocity of the need for social support from within the community of women living with HIV may have dissipated. More women are likely to live long and healthy lives, and are perhaps less likely to lose the support of their family, friends and other communities of belonging. Further, the extent to which the bonds of community are sustained through time, as perhaps women accept their diagnoses and require less social support in relation to HIV, may be questioned. This is explored in chapter seven.

The gendered experience of community is also considered, with specific reference to the experience of giving and receiving care, social networks, and how this affects a sense of community identity. There is little literature exploring women's communities in the context of HIV, in terms of these questions. From my own experience as a gender and HIV professional, there is ample practical evidence of women forming effective communities, collectivising to act together and to identify and act to meet their needs.

For example, in 2014 I produced a report with the Global Coalition on Women and AIDS, supported by UNAIDS, exploring women-led community responses to HIV and gender-based violence (Stevenson, Orza et al. 2014). The research produced case studies detailing the myriad ways in which women use shared experiences or identities to form a collective response, such as sex workers unionizing to prevent abuse, and trans women leading research to produce an evidence base to compel institutional change. Similarly, a systematic literature review examining the impact of support groups for women living with HIV found that women were at elevated risk of discrimination and isolation and concluded that support groups with other women living with HIV are effective and valuable for mitigating these challenges (Paudel and Baral 2015). There is though little qualitative understanding of the experiences of community belonging, as opposed to its impact.

As mentioned earlier, the changes in 'community' for women living with HIV as the reality of living with HIV has changed, is of particular interest in this study. The differences between activism in the early days of AIDS compared to the current moment are significant. In the initial period of AIDS, in the absence of treatment or knowledge, communities were forged in fear and urgency. Activism was about saving lives. The story of this period is only recently being told, and is emerging through cultural artefacts including films, books and documentaries. The role of women within this is contested, and often missing, with recent documentaries exploring, and taking different views, on the role of women in the early days of HIV activism.

Consider two examples that gained particular traction in recent years (though this is by no means a comprehensive review). In the 2013 documentary *How to Survive a Plague*, directed by David France, the story of AIDS Coalition to Unleash Power (ACT UP) New York is powerfully told, from the building of an activist movement to its eventual schism (France 2013). As with fictional accounts of the same period (such as the play and movie 'The Normal Heart' written by ACT UP activist Larry Kramer) there is a significant focus on the activism of gay men inspired by the devastating loss of friends and lovers, and the risk or reality of acquiring HIV. The film is noticeably lacking in depictions of women living with HIV, or women activists describing their own personal involvement or sense of loss. The women featured are instead what could be termed 'professionally involved': scientists, journalists, and others bringing skills to the movement. In the archival footage presented of ACT UP meetings and activism, there are many women present, but we hear comparatively few of their stories.

One woman who is presented as a key figure is Iris Long, a scientist who approached ACT UP and offered to support them to understand science: funding, research, reviews, approval systems and more. In so doing she shaped one of the most significant developments in the ACT UP model – the principle that the affected had to become the experts in order for progress to be made. In the film, the viewer is introduced to Long by male ACT UP activists, speaking to camera recalling their experiences in the movement. She is variously described as a 'housewife', living a 'quiet life with her husband' and 'not gay' (France 2013).

Elsewhere in the documentary, the involvement of women is suggested (for example in archival footage of protests that were jointly for abortion rights and gay rights, and frequent references to gay and lesbian activism) but the advocacy of women, the specific needs and demands of women and women living with HIV themselves are all largely absent. The conclusion of the film has Larry Kramer stating: “Every single drug that’s out there is because of ACT UP, I am convinced. It is the proudest achievement that the gay population of this world can ever claim.” (France 2013) Whilst it is evident that ACT UP was significantly shaped, led and driven by gay men (and lesbians, who can perhaps be assumed to be included in Kramer’s statement) this nonetheless seems to invisibilise the involvement and contributions of others, especially women.

In contrast, *United in Anger*, a 2012 documentary co-produced by Sarah Schulman and Jim Hubbard, provides much greater focus on the role played by women (Hubbard 2012). The film uses archival footage and oral testimony, and includes women living with HIV as well as many women activists. Schulman, an ACT UP activist, said this in an interview about women’s involvement in the movement (Filar 2014, no page number):

What was interesting was that one of the reasons that women did so well in ACT UP was necessity, because these men were desperate to stay alive and the women had a lot of spirit, so they listened to them. I've never seen gay men be so open to listening to women in my life. In our film, you see the women with AIDS you see they're leaders, you see that it was women of colour, you see it was former sex workers, former drug users, homeless women, making speeches, leading demos, being dragged away, being arrested. Because of thalidomide, women were excluded from experimental drug trials. But they're all dead now, all of those people, so the fact that that was an activist movement is unknown.

The role of women, and the women-centred campaigns they supported, were significant. ACT UP members Maxine Wolf and Jean Carlomusto described, in a 2014 panel in New York, the role of ACT UP and the New York Women’s Caucus, which campaigned firstly to simply prove that women could be and were acquiring HIV and that heterosexual transmission was possible (as earlier understandings excluded women entirely) (Riley 2014). Subsequently, the Caucus led a four-year campaign to challenge the Centers for Disease Control and Prevention (CDC) to change the definition of AIDS, to include conditions that affected women, and

ensure they would have access to social support and other benefits associated with an official AIDS diagnosis (Riley 2014). They organised educational materials, campaigns, and teach-ins, and called for a research agenda that included women.

How to Survive a Plague and *United in Anger* are very different films, though both tell the history of the same actors in the same period, the former is a very masculine tale of heroes who overcame – survived – while the latter takes a more educational approach, and portrays a narrative of a fight that is far from over. In both, women are included, but with a different sense of what roles they played and of how these roles were accessed. In the former, women won entry through their skills or knowledge, and effectively helped and supported gay men in ‘their’ struggle. *United in Anger*, alternatively, presents women in a broader range of roles including living with HIV, united in a shared anger and a fight to which they lay equal claim of ownership.

In an interview, ACT UP members Marion Banzhaf and Alexis Danzig describe the vital and equal role played by women in the movement (Wyne 2015). Their narrative points to the gendered nature of men and women’s roles in early HIV activism, suggesting there were specific issues that emerged thanks to women’s involvement (Wyne 2015, no page number):

Among other things, women brought a sense of bigger purpose. Women and people of colour geared towards intersectionality politics versus single-issue politics. Instead of just "drugs into bodies", it was the bigger picture about how to nurture and deal with the body. Women had a lot of energy. Women had been caregivers before ACT UP. Marion Banzhaf.

Routes into HIV activism were diffuse. For some, as noted here, a background in care and supporting those affected by AIDS. For others, a history of activism, whether for LGBT rights or other causes. Others were personally affected by HIV. As the epidemic changed, and treatment became available, the solidity of the early activist movement began to crumble. In the beginning, there was a clear set of shared and limited goals: people are dying, government must act, and those affected must be helped. Later, the picture grew more complex. With treatment, the nature of the fight, and the goals, changed. ACT UP itself split into factions (France 2013). There emerged a new ‘class’ of activist: paid, professional and

driven not by imminent death but by longer-term and often less personal goals. Emily Bass, an ACT UP activist, now working for AVAC (formerly the AIDS Vaccine Advocacy Coalition), describes the immediate aftermath of treatment becoming available, as a journalist covering HIV (Bass 2015, no page number):

“You’re just calling to cherry-pick for free,” one activist barked when I called to interview him for an article on anal cancer. The whole idea that anyone who hadn’t buried countless friends or patients or both was earning a living off the virus was, at that point, scandalous. This activist who had HIV, who worried constantly about anal warts and pap smears, was supposed to give me his information so that I could get paid?

With treatment, the urgency and ‘necessity’ that Schulman described, which created space in the movement for all comers, receded. There emerged a stronger sense of ‘them and us’ – those living with HIV, the spectre of acquisition or the burden of loss, and those others, whose role became more contested. ACT UP and other movements in the early years were significantly motivated by friendship, community and emotion (Gould 2015). As the HIV epidemic evolved, so did this sense of community.

The changing nature of HIV activism, the evolving role of community, and the interacting impact of gender, ethnicity, class, migration and other factors will all inform this research. While the immediate urgency generated by the deaths of fellow activists recedes to history in the Global North, new drivers and priorities have emerged. The early ACT UP activists did not anticipate old age with HIV to be an issue, because people simply didn’t live that long. Today, women living with HIV face new challenges, but the role of community, participation and advocacy persists.

3.2 Participation

Community captures a sense of belonging and shared experience, through a social structure. This can also be understood in the more political construct of participation, as an advocate or as a patient, both of which have salience in the context of HIV, and capture important aspects of experience that overlap with community. Participation contrasts with community in being an individual process, as a patient or advocate a connection with others can be beneficial but

is not necessary to the role or experience. In the following I present a review of participation in the context of HIV which considers advocacy and patient roles through the lens of 'biomedical citizenship', and consider how this may be applicable to the experiences of women living with HIV in London (Nguyen 2010).

People living with HIV are widely and increasingly considered to be the best placed to identify their needs and to ascertain the best ways of responding to these needs. The value of including their voices and experiences in research, policy and programming has been recognised at the international level, in particular by UNAIDS (the multi-agency United Nations body on HIV), as the main international sponsor of the GIPA principle: the Greater Involvement of People living with and affected by HIV and AIDS (UNAIDS 2007). The purpose of this principle is to ensure meaningful participation of people living with HIV, including through support for developing leadership and to reduce stigma. UNAIDS recommends this principle is upheld in setting funding priorities, and design and development of HIV-responsive programmes and research.

The GIPA principle is the product of activism by people living with HIV, who organised to demand their rights in the HIV response. This activism emerged in the earliest days of the epidemic, and was first encapsulated in the *Denver Principles* (1983), a declaration adopted by the Advisory Committee of People with AIDS, which calls for the rights of people living with HIV to live full lives, to access the best available treatment, to confidentiality and to be afforded dignity in life and in dying (Advisory Committee of People with AIDS 1983).

The principle of involving affected people in designing and implementing health and wellbeing policies emerged at the international level in *the Ottawa Charter for Health Promotion* (WHO 1986), and was applied specifically to HIV by a declaration made by 42 states: *the Paris Declaration* (Paris AIDS Summit 1994). This declaration commits the authoring states to meaningfully involve people living with HIV in policy formation, and to promote their ability to participate through programmes of the then newly-formed UNAIDS. UNAIDS took up this challenge through formulating the GIPA principle in more detail and overseeing its implementation.

Though the sponsorship of the GIPA principle by UNAIDS is encouraging, in practice there are a number of challenges to its implementation, as the organisation has acknowledged (UNAIDS 2007). Chief amongst these are the difficulties associated with disclosure of HIV status. Revealing one's HIV status to family, friends, neighbours or colleagues can have negative repercussions for the individual concerned, leading in some cases to discrimination, loss of home or livelihood and even violence.

Over time, the application of the GIPA principle has been expanded to include research – both clinical and social. The same challenges can apply, particularly limiting the visibility of involvement. This can also affect which people living with HIV are willing to participate, leading to challenges of under-representation of some groups. GIPA is also now complemented by MIWA – the Meaningful Involvement of women living with HIV. This highlights the need to prioritise inclusion of women, and to do so 'meaningfully'.

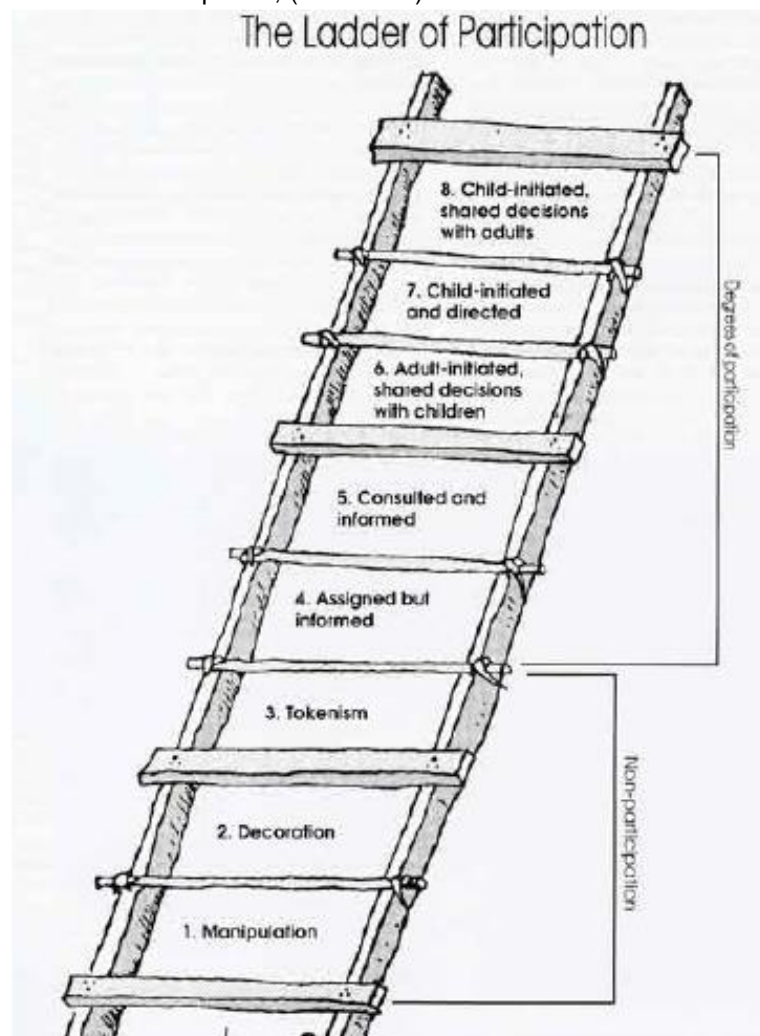
The principle of meaningful participation responds to the challenge of tokenism – where people living with HIV are included for show but given no meaningful voice in the research or project. Participation has been conceptualised as a hierarchy, emerging from child development theory, as in the ladder of participation, as shown in Figure 3.2 (Hart 1992). This was adopted and adapted by networks of women living with HIV to develop and illustrate the MIWA principle (WE CARE+ 2011).

The demand for women living with HIV to be actively involved and leading in decisions that affect them is a vital part of much global and national advocacy. In the example given, the focus is on projects and programming, where the ultimate demand is for women to be funded and supported to set and implement their own agendas (WE CARE+ 2011).

Personal advocacy for people living with HIV incorporates both social justice advocacy, such as political campaigning and rights claims, and advocacy performed within the role of patient. The clinical relationship, and the exchange between patient and healthcare worker, has been the site of significant advocacy through the HIV pandemic, particularly focused on patient empowerment, and reducing the power of the clinical provider. In the UK, some HIV clinics have

people living with HIV as part of the staff team, providing mentoring or peer support services, with focus growing on understanding the impact this has (Anderson, Anderson et al. 2015). One study suggests that patients supported by 'peer navigators', people living with HIV recruited and trained to provide mentoring services, led to patients reporting a 70% increase in service uptake, and 23% reporting significant increase in understanding of and adherence to treatment (Anderson, Anderson et al. 2015). This is an interesting example too as the 'benefits' of advocacy are understood through clinical outcomes, demonstrating how intertwined treatment and participation have become. In this sense, participation is functioning to support engagement in care, adherence to treatment and other health outcomes, rather than for social support or wider advocacy goals. The boundary between political and clinical outcomes is increasingly blurred as HIV is biomedicalised, and so biomedicalisation is an important analytical frame to consider when evaluating participation and HIV.

Figure 3.2: The Ladder of Participation, (Hart 1992)



The emphasis on the empowered patient taking informed control of their own healthcare is also in evidence in the work of networks such as ICW and the UK-CAB, which emphasise the value in patients developing expert knowledge on treatment. This can be understood in a Foucauldian analysis as being driven by a concern over the power held by the clinician and shared with the patient through a process of incentives and regulation (Bunton and Petersen 1997). This has particular potency in the context of a stigmatised condition such as HIV, especially in the early days of the epidemic when very little was known about HIV and no effective treatment was available.

Foucault's sociology focuses on the analysis of discourse, power, and governance, and has been influential in the sociology of health and medicine (Bunton and Petersen 1997). A Foucauldian analysis of healthcare and public health considers 'governmentality', which refers to the point of contact between the individual, and the actions of technologies of power. Medicalisation describes the increasing power of health professionals as social problems become 'medicalised': understood as health problems with health-based solutions, expanding the purview of the healthcare system and professionals within it into the social world (Lupton 1997). This critique, Lupton (1997) argues, can be enhanced by applying Foucauldian theory. In traditional concepts of medicalisation, medicine becomes a tool of social regulation, while medical professionals come to hold a greater degree of power over 'lay people' who lack privileged expertise. The process of medicalisation exerts particular impact on marginalised groups, as the discourse shifts from a focus on inequality and social justice to one of disease and therefore medical responses, and social justice arguments become medicalised creating a nexus of control of both medical and biomedical discourses as well as political and social justice discourses.

Lupton argues that this critique is too one-sided, failing to account for any positive outcomes of the medical encounter, altruistic motivations of healthcare staff or active role of the patient (Lupton 1997). Further, the governmental imperatives in the exhortation of 'empowerment', in controlling and regulating behaviours, are not accounted for. Lupton advocates applying Foucauldian ideas to the critique to enhance it, specifically by incorporating positive and productive functions of power within society. Power in this reading is relational, with knowledge emerging

from an interaction between those with power and those on whom it is imposed, and can be applied to supporting the patient to better understand and experience their own body and state of health. This too is an action of power, as power is unavoidable, and works at all levels. Here, the imperative regulating the 'patient' is to understand and experience their body and health.

Reading the patient as more than passive speaks to the experience of the participatory model of the HIV patient as advocate. However, the pertinence of the medicalisation critique remains. Viewed through the lens of HIV, the influence of the medicalisation critique is particularly clear. In the early days of HIV, before treatment, the role of the clinical healthcare provider was often palliative. In this context, the absolute authority of the clinician was often challenged by activists, who sought alternative routes such as advocating for treatment, or exploring alternative therapies. This was bolstered by the wider sense that governments, pharmaceutical companies and the scientific establishment were failing to react appropriately to HIV, in terms of a lack of urgency and proportionate funds and focus, underpinned by institutional discrimination against those most affected. This included doctors and the medical establishment, which from the outset of the epidemic were the target of advocacy, and demands for better research and treatment (UNAIDS 2015). The history of clinical progress in response to HIV is heavily shaped by activist input, with, for example, new prevention technologies entering clinical research as a direct result of activist demands (such as vaginal microbicides, which emerged as a feminist activist demand, and *then* became a subject of clinical studies) (Stein 1990). It is also true that activism has been co-opted to serve the interests of the institutions it targets, and the route of progress has been far from linear and driven by multiple competing factors.

For example, the authority of healthcare professionals and their role in driving forward progress in HIV care and treatment has consistently been undermined by their involvement in perpetrating stigma and discrimination, such as refusing to treat patients with HIV. For women, this has gone further in a number of cases, to a paternalist and controlling model of medical care where women living with HIV are persuaded, forced or coerced into abortions or sterilisations (Gatsi, Kehler et al. 2010). This, along with experiences of discrimination, withholding of treatment and information, advice not to conceive and similar examples, has

served, I would argue, to both undermine the authority of the medical establishment in relation to women and HIV, and to both foment and evidence a feminist, Foucauldian critique of a medicalised response to HIV.

Biomedicalisation can further be understood in a Foucauldian exploration of the concept of 'risk' and how it functions within modern public health discourses. Public health models which identify 'risk factors' expand the sphere of public health into more of individual and social life, and regulate the individual, who is defined as able to act to reduce risk (Petersen 1997). Further, this 'risk' paradigm extends the conception of the individual as exercising control over their health, as active and able to influence their health outcomes (Nettleton 1997). The individual who does not mitigate risks or adopt healthier behaviours is therefore understood as partially at fault, a failure of the will.

In the context of living with HIV, this can be seen through the increasing role of the 'expert patient', who is expected to take treatment as prescribed, attend appointments and be informed about treatment, active in managing their own care, and mitigate other health 'risks' such as lifestyle factors. As HIV has become medicalised through treatment becoming available, it has also medicalised beyond treatment, in the expectations applied to patients and their behaviour.

Research on risk and HIV has often focussed on prevention of HIV acquisition, and often therefore in the UK context on the groups most affected by HIV: gay men and African people. However, risk is also pertinent in the experience of living with HIV, both in terms of prevention of onward transmission, and in the health of people living with HIV themselves. The gendered aspects of risk, and the suggestion that individual health is contingent on managing and avoiding risk, have been explored in the context of other issues. For example, in the modern construction of pregnancy as involving the pregnant women managing and mitigating risks to the foetus, or demands on women to prevent violence by avoiding 'risky behaviours' like walking alone at night (Hannah-Moffat and O'Malley 2007). The function of risk within gendered identities is not just a modern phenomenon however, but also a product of misogyny and of experience, for example, the idea that walking alone at night is dangerous emerges through informational materials, produced for example by the police, but also through

routine experience of having been harassed or assaulted in such situations (Hannah-Moffat and O'Malley 2007). In this way, women are governed by gendered risks and constructions of responsibility, and HIV is likely to function within this, I would argue, including through notions of appropriate behaviour for women. This is explored further through women's experiences in the life story interviews and workshops, presented later in this thesis.

Risk as a form of governance is especially pertinent today as the response to HIV becomes increasingly biomedical. Advances in recent years have centred on treatment, especially the concept of treatment as prevention, where effective treatment means an individual cannot pass on HIV.

This biomedicalisation has been observed as a broader social phenomenon by a number of authors, who suggest that the modern era is characterised by the transition from medicalisation to biomedicalisation (Rose 2001, Clarke, Shim et al. 2003). This is underpinned and driven by technoscientific advances (Clarke, Shim et al. 2003, p.162):

Biomedicalisation is our term for the increasingly complex, multi-sited, multidirectional processes of medicalisation that today are being both extended and reconstituted through the emergent social forms and practices of a highly and increasingly technoscientific biomedicine.

Technoscientific advances include the increasing use of computer technology, new medical technologies and clinical innovations in diagnostics, treatment and procedures. Biomedicalisation is defined by the "extension of medical jurisdiction over health itself" as opposed to just "illness, disease and injury", leading to a commodification of health, conferring individual ethical obligations to seek, maintain and improve it (Clarke, Shim et al. 2003, p.162). This includes an extension of the medical realm to include natural processes, such as ageing. The development of biomedicalisation has (Rose 2001, p.1):

... given birth to techniques, technology, experts and apparatus for the care and administration of the life of each and all.

Clarke, Shim et al. (2003) observe five processes of biomedicalisation, each of which can be related to HIV. The first process is the expansion of privatisation and the medical industry, leading to greater stratification of access. As health is commodified, it becomes subject to inequalities in access and benefit. This can

be seen in access to HIV treatment writ large, where still in poorer countries millions lack access to the treatment they need (UNAIDS 2017). It can be seen too in localised contexts, where access to new advances such as viral load testing or PrEP⁴ can be determined by financial access, or by facets of identity (determining who is prioritised and who denied access). In turn this determines who has access to health itself, as a commodity to which people have differential access due to factors such as class, wealth, ethnicity and other determinants of health inequalities.

The second process involves a focus on risk and surveillance. As health becomes a goal, and a moral obligation, individuals are expected to act to improve it. In shifting from a disease model to a biomedicalised understanding of health as a commodity to be improved, the dichotomous split between the healthy and the ill is blurred, as everyone becomes potentially ill, subject to a nexus of risk. Being defined as 'at risk' can be stigmatising or limiting, but can also, Clarke, Shim et al. (2003) suggest, be adopted strategically and benefitted from. Think, for example, of someone with a family history of heart disease being offered free gym access. In the HIV context, the 'at risk' label can be stigmatising, but can also lead to greater material resources or access as for example in the case of PrEP in the UK, where access for gay men is greatly prioritised (Stevenson 2016). Women, at lower risk, and not defined as a 'risk group' as such, are much less visible in the debate. Understanding how risk is defined and having the tools, information and access to operationalise it, effectively those who 'do' being 'at risk' well, becomes a means to access resources, which is defining of biomedical citizenship, and is discussed further later in this section (Nguyen 2010).

The third process described by Clarke, Shim et al. (2003) relates to technoscientific advances, making identification of risk, early intervention, and health promoting treatment ever more possible. The fourth process describes the function of information and knowledge, and the increasing forms of each, as well as sources to access them. The original medicalisation model of the expert healthcare provider and inexpert patient is increasingly subverted as information

⁴ PrEP, or pre-exposure prophylaxis, is the use of HIV anti-retroviral medication for prevention of HIV acquisition in HIV-negative individuals.

becomes accessible from a wider range of sources and via different media. As related above, this is particularly applicable to the 'expert patient' and treatment advocate models in HIV. The form that knowledge takes has also undergone significant change, with risk and health status increasingly understood not by the embodied experience of symptoms, but by molecular diagnostics dependent upon the expertise of the medical professional. Now, people living with HIV measure their state of health via CD4 counts and viral loads, determined by health workers. The ability to access this knowledge and to understand and engage with it is differentially available. It also has consequences for the power balance between doctor and patient, as the ability to understand, or be seen to understand, this information will affect the medical encounter. A good patient, and good biomedical citizen, is able to understand this information, and to therefore have greater parity in their relationship with the doctor.

Finally, the fifth process describes the transformation of bodies themselves, as we shift from control over bodies to the possibility of transforming bodies to have certain properties or identities. Preventative interventions are one facet of this, particularly health promotion based on identification of risk. As noted though, this can be both including and excluding. For women in the UK, not recognised as a 'risk group', and so not targeted for prevention interventions or understood as 'most affected' by HIV, the risk paradigm is often a barrier to access to health interventions, not a facilitator.

Rose (2001) describes the process of biomedicalisation as that of 'life itself' becoming politicised – subject to political authority and intervention. He traces the history of this from 18th century concerns with promoting the 'fitness' of the population, to a modern incarnation where politics is concerned with all aspects of human life, health and disease (Rose 2001).

In Rose's rendering of risk as a function of biomedicalisation, he points to the dangers of essentialising and individualising conceptions of risk, and how these can lead to control, imposition and even eugenicist practices (Rose 2001). It is interesting that in Rose's account, eugenic practices such as forced and coerced sterilisation are discussed as belonging to the past, where in fact these practices continue, and one group affected is women living with HIV (Gatsi, Kehler et al.

2010). The possibility of vertical transmission of HIV from a woman to a baby has given rise to brutal consequences for many women, both forced sterilisations and abortions, and enforced treatment, in the context of a paternalistic instinct to 'protect' the foetus or a more malign impulse to prevent women living with HIV from reproducing. In the UK, many women living with HIV have experienced being discouraged from conceiving, or in some cases advised against continuing with pregnancies, with far-reaching and potentially devastating consequences (Welbourn 2009). For older women living with HIV, this is a phenomenon that may have affected them, and a number of life story interview participants described these experiences.

Similarly to Clarke, Shim et al. (2003), Rose (2001) identifies a shift towards a view of health as broad and achievable, with individuals as active partners and producers in the pursuit of improved health. The identification and attribution of risk depends upon a series of actions and conclusions, which determine the future likelihood of ill health and therefore which actions are appropriate in the present. Multiple actors are involved in this process, including the individual themselves. Rose suggests a range of challenges inherent in the risk paradigm: the accuracy of risk calculations; generalisability; false positives and negatives; the moral push to subject to medical authority once risk is identified; the impact of risk attribution on identity, including stigma; and state control and surveillance. Each of these can be seen in the HIV context. Those defined as at risk of acquiring HIV are expected to modify their behaviour, submit to frequent testing and health promotion, and even to take medical treatment to prevent, rather than treat, disease. And those not deemed to be at risk are not targeted or given access to resources or information. For example, one study with people over 50 diagnosed late with HIV found that limited knowledge of HIV prior to diagnosis, beliefs that HIV primarily affected communities to which they did not belong, and low actual or perceived risk were associated with testing for HIV (Youssef, Wright et al. 2018).

The individual action and moral imperative to seek and improve health is described by Rose as 'ethopolitics', or 'a politics of life itself'. The body is itself politicised, as both the individual will to health, and the collective function of belonging to a group affected by health in specific ways, plays out. This

collectivism is of course particularly in evidence in HIV, as previously discussed.

Rose describes the process as (Rose 2001, p.19):

Individuals who identify themselves and their community through their biology challenge the vectors that lead from biological imperfections or abnormality to stigma or exclusion. They use their individual and collective lives, the evidence of their own existence and their vital humanity, as antagonistic forces to any attempt to re-assemble strategies of negative eugenics within a new exclusionary biopolitics. They demand civil and human rights for those whose lives, previously, were deemed less worthy of life. They call for recognition, respect, resources, research, control over medical and technical expertise. As somatic individuals engage with vital politics, a new ethics of life itself is taking shape.

The ways in which this plays out in the context of HIV can be seen in the forms of participation which have emerged and the value ascribed to them. The history of this association is explored by Vinh-Kim Nguyen (2010), drawing on his experiences working in the HIV response in West Africa in the period 1994-2000, during which effective antiretroviral treatment emerged. He explores the context with a reflexive viewpoint, as a Western clinician straddling the contexts of West Africa and Canada, with the access, knowledge, and position this gave him. Nguyen (2010) describes how, as treatment became available, access to it was subject to a series of calculations, effectively 'valuing' different lives differently. So wealthy westerners received access to drugs while millions of Africans died. Even where treatment was available, scarce resources necessitated a process of rationing, and determining who would have access: a process of 'triage' where calculations were made to determine who should be treated (Nguyen 2010). This power to determine who would be treated, and by extension, who would live, he terms 'therapeutic sovereignty' (Nguyen 2010). Clinical trial recruitment, programming (often internationally funded) and treatment activism all developed different criteria for treatment access.

Nguyen (2010) charts the impact in this process of the emerging prioritisation of self-help, support groups, and the ability of individuals to tell their 'HIV story', which often was the price of access. This, along with the impact of HIV and its designation as a political and global emergency, gave rise to a 'therapeutic citizenship' (Nguyen 2010, p.103):

This happened as people diagnosed with HIV transformed into activists who demanded access to treatment, articulating their claims based on the official declaration of a state of emergency.

Advocacy, and an HIV community, through this process adopt some functions of the state, operating a parallel health system according, in this case, to the policies and priorities of external foreign aid organisations and other actors. Older structures and health services are effectively side-stepped, and potentially break down. HIV is exceptionalised, and the act of being an 'HIV patient' differentiated from that of other patients of other conditions. HIV becomes then an article or facet of identity, leading to different systems and points of access.

The medicalised response to HIV and the production of therapeutic citizenships can also be seen in the 'cascade of care', which evaluates HIV care through a model from diagnosis, to engagement in care, to treatment and finally undetectable viral load (Paparini and Rhodes 2016). Given the necessity of patient engagement in achieving this outcome, Paparini and Rhodes (2016) argue this is inevitably a political process, contingent on discourses of patient responsibility and expected behaviour. They draw on ideas of biological and therapeutic citizenship, to discuss the concept of 'HIV patient citizenship'.

In the era of the HIV treatment cascade, and globally agreed targets based on this model, the role of the patient in engaging and fulfilling each step of the cascade is key (Paparini and Rhodes 2016, UNAIDS 2017). In the context of the re-casting of HIV treatment as prevention, and the 're-medicalisation' of HIV, the cascade has clear limitations (Paparini and Rhodes 2016, p.2):

First, the narrow focus on viral load progression (from detectable to undetectable) detracts attention from the broader aspects of HIV as a health and social condition, and not only a virus. 'Treated HIV' represented as a product of the care cascade is blind to the complex of individual and social practices, which situate HIV and its care relative to wider definitions of 'health'. Second, viral suppression is not a 'goal' that needs to be reached, but rather a 'state' that must be maintained over time via ongoing systemic care provision coupled with continuous patient re-engagement. System- and patient-components and relations are clearly susceptible to multiple changes. Third, by delineating the accomplishment of viral suppression as and for public health control, the cascade distinguishes success and failure, of services and patients alike, in stark biomedical terms.

To explore the implications of HIV patient citizenship in the context of the HIV treatment cascade, Papparini and Rhodes (2016) reviewed and synthesised social science literature on therapeutic and biological citizenship, HIV treatment and adherence and HIV care engagement. They identified three themes: patient engagement; therapies and politics; and biosociality and responsibility (Papparini and Rhodes 2016).

With regard to the first theme, the review found a conflict between treatment adherence and the maintenance of health, and avoiding treatment due to side effects which compromised health, including the ability to work. In this case, the medical view of health, and the individual's experiences and expectations of health, differ, leading potentially to reduced adherence or opting out of treatment entirely. However, this 'deflected' engagement can still accommodate the desire and belief amongst the individuals living with HIV that adherence, and fulfilling the demands of engagement in the cascade of care, are ideal, and to be striven towards even if practical barriers prevent achieving this. Alongside these practical barriers, meeting the demands or submitting to the authority of other actors outside formal medicine, such as family, religious leaders or communities, illustrate that different forms of agency and authority are at play, which the treatment cascade fails to account for. Additionally, the uncertainty of treatment access, supply, side effects, efficacy and outcomes, all contribute to the accommodations that people living with HIV make to engage with treatment. In this context, tests of viral load or CD4 counts become measures of discipline, revealing the extent of patients' engagement and compliance (Papparini and Rhodes 2016).

The difference between health as experienced by the patient, as being and feeling well and able to engage in normal activities of life, and health as defined by the technoscientific measures of viral load and CD4 count, demonstrates the limitations of biomedicalisation, in that the complexity of the individual life and experience is not fully accounted for. This emerged in interviews with women presented later in this thesis, where side effects and challenges taking tablets sit alongside understanding of the importance of treatment and represent a challenge to achieving and maintaining health.

Therapeutic citizenship also includes the generation of communities around the shared condition (Nguyen 2010, Papparini and Rhodes 2016). However, in their review, Papparini and Rhodes (2016) find that increasingly, HIV treatment is individualised, and the discourse beyond healthcare and the patient role is reducing. In tandem, NGOs institutionalise and become closer to the state, focusing on treatment and health over advocacy. With the normalisation of HIV as a chronic health condition, the basis for therapeutic citizenship and for HIV 'community' is undermined (Papparini and Rhodes 2016). This suggests an important question, to what extent is HIV 'community' for women ageing with HIV in London undermined by biomedicalisation and normalisation of HIV?

Biosociality, the process of forming bonds and collectivity through shared biological experience, has been described as emerging through HIV, and also, the experience of HIV treatment, however (Papparini and Rhodes 2016, p.10):

... many studies reviewed here unpack and contest the idea that a new sociality can be forged via HIV and ART. HIV stigma is not seen as a cohesive force for the stigmatised but as an ostracism leading to self-silencing. New forms of HIV-related sociality are thus described as a product of the re-shaping of existing social ties rather than of biological connections.

This is demonstrated in studies that find existing family or community ties, friends and acquaintances, are influenced by shared experiences of HIV but also other pre-existing experiences, and are more powerful than new links formed just by HIV and an individual patient experience. Disclosure avoidance and desire to return to normality further inhibit solidarity and biosociality (Papparini and Rhodes 2016). Over time, these pre-existing bonds intersect with biosociality, but they are not immediately replaced. Of note, the studies cited by Papparini and Rhodes (2016) in this argument are drawn from African countries and other settings with high HIV prevalence, so the experience may be dissimilar in the case of low prevalence settings or communities. This possible difference is explored in relation to the question posited above, in chapter eight of this thesis.

Papparini and Rhodes (2016) conclude that in the context of dependence on ART provision for survival, therapeutic citizenship might in fact be more properly understood as 'therapeutic clientship' whereby the 'client' has to fulfil certain roles in order to access the treatment they need, and wider rights claims are

limited by this dependency. They suggest that the concept of therapeutic citizenship may capture the impact of HIV as an extraordinary global event, and the disruptive force of new systems of funding and delivery of services, while not accurately capturing the experiences of people living with HIV in local contexts.

While the links between the 'politics of life itself', risk and therapeutic citizenship, can be seen in the context of high prevalence settings, or high-risk groups, how this functions for women in the UK – a low risk group in a low prevalence setting, with excellent access to treatment and care, is perhaps less clear. However, in a 2013 study re-interviewing participants from an earlier project, Corinne Squire charted a form of what she terms 'biological citizenship' among people living with HIV in the UK (Squire 2013). She identifies a disconnect between the holistic descriptions of themselves as rounded people offered by her research participants, and the medicalised construction of 'patients', which, she suggests, demonstrates a form of resistance to an increasing medicalisation explicit in their descriptions of changing interactions with health services. The process of normalisation through medicalisation of HIV as a long-term condition comes with caveats, which Squire summarises as the 'responsibilisation' of the person with HIV, as assuming responsibilities to be an engaged, 'expert patient' and to modify their behaviour to prevent transmission. This operates as a form of control, although can also be enabling in creating spaces for agency.

Squire (2013) identified a particular shift between these interviews and her earlier data, from a focus on entitlement to one of gratitude, a change from a demand for particular rights, services, and treatment to a displayed need to express gratitude for what is given. She suggests this is related to the changing national financial situation and a political climate of personal responsibility and cost effectiveness, amid reductions or rationing of budgets. HIV citizenship here becomes more individual and social, and moves away from the political. The sense of gratitude – of receiving something other than, or perhaps more than, that to which one is fundamentally entitled, runs through the accounts of Squire's participants. This suggests a central conflict in the experience of being a patient in HIV care today: it is difficult to conceive of a grateful patient as also an expert and engaged patient: challenging, informing and demanding. The conflict between these two roles is clear in many of the accounts that Squire shares. It

resonates also with Nguyen's (2010) description of an HIV citizen in a resource-limited setting where access to treatment is conditional on the adequate performance of a role, and the beneficence of others. Squire's participants in some cases echo this, yet also assert a degree of activism around seeking better treatment or services. The two strands are conflicting, yet co-existing.

Squire analyses her interview data against growing neoliberalism: that people are individualised, deemed responsible for their own wellbeing and ability to prosper. She suggests that the neoliberal model is inadequate, in that it fails to account for features that inevitably accompany yet also challenge it. So, in her data, individuals describe their individual, small-scale or informal activism providing social support networks, for example, and these are a form of activism that neoliberalism cannot account for. It could also be argued, however, that resilient and self-sufficient communities are a neoliberal imperative, but the tension lies in the role of the individual as activist within it.

The role of the 'expert patient' emerged in Squire's (2013) research in accounts of being 'proactive', that is, seeking out treatment and other medical information, and building knowledge on scientific developments and policy. In this way patients practise a form of activism in regards to their own care, and seek to be engaged and actively making decisions. This could be challenging in practice, given the volume of information and the time and resources necessary to access it, as well as the emotional labour involved in enacting it. Participants described difficulty performing the 'engaged patient' role, as both emphasising an HIV-related identity that was already potentially overwhelming, and forcing the patient to adopt a professional responsibility that ought to rest with doctors.

There is a tension between the 'expert patient' role, now heavily promoted by HIV organisations and advocates, and the reality of fulfilling it in the context of the significant resource burden it poses. There is both a regulatory and a neo-liberal imperative driving this promotion of the 'expert patient'. Many HIV treatment advocates now perform this role professionally, while the vast majority of people living with HIV do not make their salary from such expertise. This is a fairly obvious point to make, but it is worth pausing to consider how personal activism has changed since treatment became both readily available and highly

effective. Before treatment, people were dying and advocacy for treatment the only avenue open. Now people live long, full lives with HIV, maintaining jobs, relationships and other social connections, yet at the same time are being asked to become highly skilled and informed in technical medical matters.

Further, the purview of HIV activism has increasingly narrowed to focus on treatment, moving away from earlier forms of HIV advocacy, as evidenced in *United in Anger* which undertook a more structural analysis of the wider forces driving the HIV epidemic and inequities in HIV acquisition and access to treatment and care (Hubbard 2012). Wider social inequalities and forces such as misogyny, homophobia and xenophobia are de-prioritised in a neoliberal focus on getting pills into bodies, and becoming an 'expert' in this function.

For many this level of engagement as a patient will simply not be achievable, but as Squire (2013) notes, this does not mean that they are not performing as activists in other ways. In particular, through engaging with and acquiring knowledge through HIV organisations, providing a framework outside of patient status, and a platform to, for example, demand alternative treatments which may be more expensive, or to change doctors if unhappy with the care being offered. The tension here could perhaps be understood as between an individualised HIV citizenship, and a collective, political construction of it informed by wider structural inequality. Though both contain elements of the other, it could be seen that the former is more common now, and the latter was dominant in the pre-treatment era (Paparini and Rhodes 2016). This suggests avenues to explore in my research, particularly the extent to which older women living with HIV recognise or identify with an HIV community, and how they define their own relationship to it, and whether this has changed.

Squire (2013) also observes a broader shift to individual voices from collective advocacy, noting how many HIV organisations are now positioned less as campaigning forces than previously, and seek to work more in partnership with authorities. This reflects my own personal observations, of organisations increasingly depending on statutory funding, and working with policymakers rather than advocating to challenge them. It is also observed at the global level in relation to both grassroots and larger NGOs (Paparini and Rhodes 2016). This

suggests a shift towards an individual form of biomedical citizenship, away from a collective sense of belonging to an HIV community. In this context, activism can be understood as asserting citizenship and individual experiences.

A similar trend from community to individual was also suggested by Squire's (2013) participants in relation to support offered to people living with HIV, which has shifted, they suggest, towards 'self-help' models that are time-limited, in stark contrast to older models of informal peer support settings which were open for as long as wanted or needed. Squire observes in her participants that this new model seems effective for those with existing, external support networks, while those with limited support and resources were far less able to benefit.

The extent to which this shift can be observed in the stories and experiences of women ageing with HIV in London is a key question for this study. Whether women's experiences of community in relation to HIV have changed, and how, and in what ways 'community' is or has been relevant to them, is explored in chapter eight. The experience of HIV as an individualised biomedical citizenship, or as a communitarian experience, is considered through the life stories of women diagnosed at different stages in the HIV epidemic. The extent to which a political form of advocacy and participation is redolent in accounts of individual and community experiences is also considered. This will be explored in relation also to the work of Emejulu and Bassel (2018), who suggest that 'care for others' and solidarity through shared community is a radical act that allows for political agency and challenges to dominant narratives, through advocacy and participation.

Resonating with both Nguyen (2010) and Squire (2013), the function of the HIV story – one's personal journey acquiring and living with HIV and knowledge about it – as a unit of currency and a tool of activism does resonate with my own research experiences. It is quite common for people to refer to 'my story' in language that suggests a distinct product, that is handed over in a form of exchange. I have heard this in discussions about access to HIV support, engaging with the health system, with housing and immigration processes. In these exchanges, the story is the price to be paid for the outcome or resource that is desired. The story here, in the telling and the re-telling, ossifies into an

object, that is passed over and over. How memory functions in relation to traumatic or difficult experiences, and how over time details are lost or stories change in the process of re-telling, was described by Primo Levi in his work exploring memory as a Holocaust survivor (Levi 1988, p.16):

It is certain that practice (in this case, frequent re-vocation) keeps memories fresh and alive in the same manner in which a muscle that is often used remains efficient; but it is also true that a memory evoked too often, and expressed in the form of a story, tends to become fixed in a stereotype, in a form tested by experience, crystallised, perfected, adorned, which installs itself in the place of the raw memory and grows at its expense.

Similarly, in peer support settings, the story is shared to buy access to a social space and support. I have heard many activists over the years relay their story in conferences and other settings, and have been struck by how similar the recounting is, time after time. As a researcher who seeks to find and create narratives and tell stories, I am interested to understand how the story is created, how it is used or traded, and how in the research process it might be possible to find new ways of telling, of travelling together to form a narrative that is not beholden to the imperatives of access or resources (though of course is shaped by other objectives). This is supported by adopting an assets-based approach that seeks to move away from needs and create a more complex, comprehensive picture of experiences. Using these methods I will consider how participation and community operate for older women living with HIV, and how this supports an understanding of therapeutic citizenship in this context. Through the primary data presented in chapter eight I will consider the different forms of community, activism, advocacy and participation that emerge in women's stories, how these are mobilised and what forms are discernible.

3.3 Theoretical framework

I will draw on the theoretical concepts of participation and community outlined in this chapter, particularly the concept of biomedical citizenship. The extent to which HIV status mediates relationships with other individuals and actors, will be explored. I will consider this in relation to belonging and community, and consider how community is formed and sustained for older women living with HIV.

Advocacy as an expression of both biomedical citizenship and community belonging will be a core thread to the theoretical framework adopted.

Community in different forms will be considered, drawing on interviews and workshops to consider which communities women feel a sense of belonging to, how they are formed and what role they play. The extent to which a community of women living with HIV is evident will be a particular consideration, as will how this is constituted. In chapter four, I detail the reflexive approach I take in this research. My roles as a researcher and advocate give me a place within the community of women *and* HIV, which differs from but overlaps with the community *of* women living with HIV. The extent to which this community is discursively produced and altered through this research will be considered, as will my role within it.

The theoretical framework I am adopting is deliberately limited, as I seek to do research which is adequate in practice, using a realist approach which is tested by application and outcomes in the 'real world'. I have therefore outlined the theory I adopt in detail, and the application of it will emerge in the actual 'doing' of the research and be discussed in the findings chapters that come later in this thesis. This reflects the feminist approach I adopt in this research, and particularly a 'promiscuous feminist methodology' which recognises that the practice of research is often messy, and rarely adheres to 'off-the-shelf' theoretical paradigms (Childers, Rhee et al. 2013). This research is feminist-oriented as it attempts to do research as advocacy. It does not attempt to engage feminist theory beyond the feminist position that ways of doing research and ways of knowing are open to challenge and change.

This feminist orientation is adopted due to what has emerged in the empirical and conceptual literature reviewed. The empirical evidence demonstrates an under-representation of women as participants and the focus of studies, as well as in the analysis where women as a group are often not considered. This means the issues for women ageing with HIV are unclear, and as demonstrated through the participatory review of the literature I conducted, key questions and issues for women are quite absent from the evidence base. The participatory literature review also highlighted the absence in the existing literature of participatory

research that involves women in shaping the evidence base. I therefore adopt a participatory, feminist approach to deliberately do things differently, with the hope of better including women and through this more adequately exploring and understanding their needs and experiences.

Within this approach, theory will be vital in analysing and understanding the qualitative data I gather, but I seek to maintain the feminist approach outlined above, and therefore the theory will be tested in application, and the framework emerge organically with the research. In some forms of research, the theoretical framework is used like the skeleton frame in a building – it goes up first and stays put, rigid, and the research is implemented around it as to a blueprint and specifications. In feminist, especially promiscuous feminist research, you are not building to a blueprint. Instead, it is more like gardening. Think of bamboo garden canes, which support and help plants to grow. They have a function, and a role in the shape, direction and growth of the plant, but they are led and follow the organic growth of the flower, and when they no longer hold the flower up, you replace them.

3.4 Research objectives and questions

The aim of this research is to explore the experiences of women ageing with HIV in London, and to elucidate a clearer understanding of and insight into these experiences than is currently captured in the evidence base. Through a feminist and assets-based approach, and using participatory methodologies, I seek to gather insights into what it is like to be an older woman living with HIV, including both challenges and opportunities, and experiences of community and participation. The main research question explored in this study is:

What are the experiences of women ageing with HIV in London? How are these experiences understood and expressed?

With further sub-questions:

- How are these experiences mediated by gender, sexuality, ethnicity, migration status and experiences, or other factors?

- How have women adapted to ageing with HIV, including experiences of age-related conditions and other co-morbidities, home and residential care, and economic and social issues?
- What assets do women hold and use to mediate their experiences, and in what ways are they used? Is the notion(s) of 'community' amongst these assets?
- How is the concept of 'community' relevant? What constructions of 'community' can we discern in the experiences, accounts given and discourses employed by older women living with HIV?
- How have collectivities of older women living with HIV, and others, responded to growing older with HIV, for example, through peer support and activism? Does this suggest a 'biomedical citizenship' and how might this function? How does this counteract or mediate notions of 'community' for women living with HIV?

These questions will be explored in relation to the concepts of 'participation' and 'community' as defined and explored in this chapter. In addition, they will be considered and reflected upon directly within the research by participants themselves. The questions to be explored also underpin the methods I adopted in this research, described in the next chapter.

4. METHODOLOGY

In keeping with the feminist approach adopted in this thesis, the methods used are as important as the findings. Consequently, I now present an overview of the methodological considerations and literature supporting the methods adopted in this research.

4.1 Methodological considerations

The production of research and knowledge about HIV has been consistently contested, and emerged through a negotiated process shaped by political, economic, cultural, social, and historical factors (UNAIDS 2015). As well as scientists and academics, activists played a key role in this process, creating a complex political context in which research is designed and conducted.

This context is contested, while the research environment is politicised in the HIV arena, the actual impact of this activism is often unclear as the production of scientific knowledge is rarely neutral, as there are always political forces influencing the production of research, as outlined in the previous chapter on the theory of participation. Activist discourses are diverse and influence outcomes in various ways, as can be seen currently as biomedical approaches increasingly dominate research, reflecting one particular strand of advocacy that now includes clinical scientists alongside community members, who push for more and better biomedical advances. Yet this is in direct conflict with other activist discourses, particularly feminist discourses, which call for social innovations to be prioritised over the biomedical. It has been observed that these communitarian approaches are ceding ground to increased priority for biomedical interventions (Nguyen 2012, Keogh and Dodds 2015). The tension between social and biomedical approaches is a significant issue for the HIV response, and is relevant to this research, which considers both the clinical process of ageing with HIV and the social, lived experience of it.

Nguyen (2012) outlines the history of social scientific involvement in the HIV response, charting the backdrop of conservative, reactionary media and political environments in the early days of HIV, and the role of social science including feminism, queer theory and anti-intolerance in promoting progress. This social

approach, seeking to situate HIV research in a broader analysis of social drivers and power, emerged from both activists and social scientists, promoting the idea of health as a human right. This shaped an activist approach developing and incorporating Nguyen's (2010) 'biomedical citizenship', including a right to access treatment and care, and responsibilities around prevention, which was vital in achieving access to treatment for people living with HIV in the global South (Nguyen 2012). More recently, this paradigm has shifted, as described in the preceding chapter, to a neoliberal, individualised, biomedical-centred approach which casts people living with HIV in a client role – receiving services, not realising rights – and risks people being blamed for failing to access or adhere to treatment or prevention, as a form of discipline and regulation (Squire 2013, Papparini and Rhodes 2016). In this context the influence of activism is unclear, and it should be noted that research develops under a range of drivers, among which activism may be included and will exercise more or less influence depending on who is developing the research, what the research involves and why it is being conducted. These questions are key to defining the participatory nature of this research, explored in detail in this chapter.

As described in the preceding chapter, the GIPA principle and Community Advisory Boards emerged from the principle of including affected people in research. Of course, such approaches can also function to control and regulate the behaviour of people living with HIV, layering into the role of the 'good patient' not just expertise, which is a heavy burden to carry, but an expectation of active involvement in and oversight of research (Squire 2013). Choosing not to engage with such structures can be challenging. More, these principles are rarely implemented fully and often serve disparate ends, not all in the interests of people living with HIV. However, their development suggests some drive towards shifting power to people living with HIV. This all speaks to a political desire to see research as participatory, respectful, and co-produced, rather than 'extractive' or worse, exploitative. Overall, there is a demand that research is done *with* or *by*, rather than *to*, people living with HIV.

Consequently, my research was undertaken with a primary motivation to seek participatory and respectful methods, which have informed both the theoretical and political framing of the research, and the way in which it was conducted. This

led to the decision to adopt gender-based and feminist methodologies, and an assets-based approach.

4.1.1 Feminist and gender-based approach

This study focuses on women's experiences, through interviews and workshops with women. By specifically exploring the experiences of women, it aims to fill a gap in the existing literature, where previous studies have not undertaken analysis of women as a group. More, it speaks to a larger gap in the evidence base on HIV in the UK, which focuses on men who have sex with men, and African people (men and women), rather than on women as a group. This leaves gaps in understanding and in the experiences captured, for example, around explicitly gendered experiences of ageing such as menopause, social pressures and judgments, and provision of care to others.

A focus on women is not in itself though a gender-based approach to research. This goes further, to a research framework which highlights an understanding of gender as a process, an activity and an influence on the decisions, opportunities, expectations and behaviours available and accessible to individuals in their lives. A feminist research epistemology also involves analysis of the gendered ways structural factors and structural inequalities influence experiences and provides insight into how these play out, taking into account social, political and structural dimensions in addition to the personal. Within the methods utilised in this research project, especially life story interviews (described later in this chapter), a gender lens and analysis is particularly appropriate (Järviluoma, Vilkkio et al. 2003, p.46):

A text about life, whether we call it a life story or an autobiography or some other name, always refers to a life lived, to gendered life events and to a gendered bodily subject, producing a narrative of that life.

Gender and sexuality emerged as influential research topics through the late twentieth century, through contested, varied viewpoints around the connection between gender and sex, the influence and meaning of gendered language, and how gender is enacted or assumed (Glover and Kaplan 2008). While not a study of feminist theory, I adopt a feminist approach in my research. I am interested to explore how gender is understood, and how relevant it is to a sense of

participation or membership of a community, including the identity of members of that community. Further, the interaction between personal narratives and the individual's understanding and analysis of gender and gender roles, in relation to HIV and ageing, are objects of exploration in this study.

My research is rooted in a feminist epistemology, which describes an approach that aims to challenge the academic orthodoxy, recognise and engage with the function of power in research and adopt a reflexive praxis. Engaging with gender itself is one element of this, but feminist methodology goes far beyond this (Childers, Rhee et al. 2013, p.517):

The conflation of feminist methodology – understood as a theory, method, practice, and becoming – with the demographic or “descriptive” and generalized category of “women” or “feminist” is not just a textual, metaphorical, or philosophical problem, but, indeed, a political and methodological problem. It depoliticizes and limits the specificity of the politics and ways of living, being, working, and becoming developed by “feminists” but which is not gender-dependent.

The feminist approach adopted is explored further in the discussion of reflexive practice later in this chapter.

In addition to forming part of the epistemological framework, gender is an object of study in this research, which explores questions including how women's experiences of ageing, and the narratives of ageing they construct, are influenced by gender, including gender norms and gendered expectations of behaviour. The feminist approach I adopt includes critically engaging with ideas around gender and power, utilising gender as an analytical frame to understand the meaning and narratives assigned to individual experiences and life histories. Gender will here be used as a route into understanding the individual construction of identity. Qualitative research will elicit further understanding of the role gender does or does not play and how this acts in influence and tandem with other facets of identity. Gender identity, as with all aspects of identity, is a process, formed and forming over time, subject to continual change (Järviluoma, Vilkkio et al. 2003). This adds to its usefulness in considering ageing, including a life-stage understanding of ageing as a process and transition, rather than a ‘milestone’ approach which understands ageing as an event.

Gender and feminist approaches to research have evolved, from an initial focus on gender difference and binary comparisons between 'men' and 'women', to a focus now on diversity of gender and sexual identities and practices, with an increased focus on sexuality and its relationship to gender (Cameron 2005). Cameron (2005) described this as the postmodern feminist approach, building on the feminist foundation that gender is socially constructed and played out in the construction of identity and relationships. Cameron describes five key elements of the postmodern feminist approach, which are adopted in this research:

- 1) Disputing the foundational status of sex: questioning the distinction between sex and gender on the basis that sex is also socially filtered.
- 2) Performativity: gender identity is produced by the activities and actions involved in 'doing' gender.
- 3) Diversity: there are multiple possible gender identities or positions, shaped by other elements of identity including ethnicity, class and other factors, and there are differences both within and between groups.
- 4) Local explanations: identity is produced in specific contexts and therefore there are local, not universal, explanations and definitions.
- 5) 'Liminal' focus: consideration of queer identities, and relation of gender to sexuality and heteronormativity.

Women living and ageing with HIV are diverse, with different identities, experiences and social roles. In the conclusion to this thesis I will analyse the data collected through workshops and life story interviews against this framework, particularly exploring how gender is described and experienced in women's stories of ageing with HIV, and how their experiences are shaped by social, cultural and political positions and experiences such as ethnicity, class, sexuality and migration. In this framework, points two, three and four are especially relevant to my analysis. Women's experiences of HIV, from diagnosis to living and ageing with the virus, intersect with their experiences and their contexts. Point five is also relevant, as for women in HIV data and policy, heterosexuality is often assumed, based on presumed transmission route rather than women's own descriptions of their identity (Sophia Forum and Terrence Higgins Trust 2018). In response to this, I considered sexuality in recruiting to my

study to ensure diversity of participants, and explore how sexuality influences women's experiences.

The postmodern feminist approach moves away from comparing a generalised 'male' and 'female' experience and creates space to explore and understand gender as one strand within a multifaceted identity, and to explore how gender and femininity is understood and defined for individual women in local contexts shaped also by culture, class and other factors within a wider conception of agency.

The qualitative data in this study was collected and analysed using feminist methodology, which understands gender as a function of how we perceive our own experiences and form relationships, and communities (Järviluoma, Vilkkio et al. 2003). Gender is understood in a context influenced, mediated and reflected by socio-economic position, oppression, violence, culture, migration, sexual orientation and gender identity. This is not simply a discursive approach, but recognises gender is a product of all these social factors, that emerges and re-emerges in the interaction between these social forces.

Three reasons support the adoption of a gender-based and feminist approach in this study:

- 1) Gender is under-addressed in the UK HIV response, including research. The public health approach identifying most affected communities by transmission risk groups means little attention is paid to women *qua* women. This is increasingly recognised within the UK HIV sector (NAT 2015b, p.3):

The UK's response to HIV has never been driven by a gendered analysis on why men and women acquire HIV through heterosexual sex, despite such an approach becoming the norm internationally. Such an analysis highlights the impact of gender norms and identities on health outcomes – and is especially relevant when considering sexual relationships between men and women. The gendered perspective is by no means completely absent from our understanding of the epidemic, and there are important contributions made to it by clinicians, researchers, community organisations and networks such as PozFem and the Sophia Forum. But it has never been truly integrated into our prevention response. This may be because in the context of the UK epidemic - which is not a generalised one - heterosexual HIV

prevention has focused primarily on ethnicity and/or place of birth as key predictors of risk.

- 2) Ageing can be seen as a gendered process, including biological processes such as the menopause, as well as social expectations and experiences of ageing (such as social norms around physical ageing).
- 3) HIV can be seen as a gendered experience, with acquiring, living with and ageing with HIV all potentially affected by gender norms and experiences.

In relation to point two, the gendered nature of ageing itself, there is a growing body of research exploring connections between gender and ageing. Women's experiences of later life are subject to transitions around which women construct and re-construct identities, with similarities and differences influenced by class, disability, race, ethnicity and sexuality (Bernard, Phillips et al. 2000). Gender intersects with ageing across different dimensions. For women, this includes greater likelihood of experiencing disability, requiring care and facing economic disadvantage, compared to men (Arber, Davidson et al. 2003). Women are also more likely to experience widowhood, with concomitant changes in social connections and support (Arber, Davidson et al. 2003). Social attitudes including pressures to 'look young' and changes in health, disability and economic position all shape women's experiences as they age (Bernard, Phillips et al. 2000). Along with gender, class is also an important determinant of advantage or disadvantage in older age (Arber, Davidson et al. 2003).

Evaluating the body of research on gender and ageing, Bernard, Phillips et al. (2000) highlight the dominance, in the UK, of research focusing on white, heterosexual and middle-class women, and of research that pathologizes women's experiences. Arber, Andersson et al. (2007) identify dominant trends in research on ageing and gender as including a focus on economic perspectives and disadvantages experienced by women, and call for research on other types of social advantage and disadvantage including ethnicity, migrant status and class. Care responsibilities, interruptions to paid work and pension entitlements, greater likelihood of living alone in older age, and other differences contribute to women's disadvantage in older age and warrant further study (Arber, Andersson et al. 2007).

Situating my own research within this wider body of work, I aim to explore the intersecting impact of socio-economic status, race, ethnicity, migration, class and sexuality in women's experiences of ageing with HIV, and to understand how gender influences these experiences. I further explore participation and exclusion as experienced by older women living with HIV, responding to the call for focus on class and other social categories in the ageing and gender literature.

Walsh, Scharf et al. (2016) argue the concept of 'social exclusion of older people' has potential to improve understanding of and responses to disadvantage in later life. They identify six domains of social exclusion in older age: "material and financial resources; social relations; services, amenities and mobility; civic participation; neighbourhood and community; and sociocultural aspects of society" (Walsh, Scharf et al. 2016, p.87). The authors suggest more work is needed to understand how gender (among other identities and social positions) interacts with social exclusion and the multidimensional impact of these alongside ageing processes.

In exploring these issues in my research, the influence and impact of gender is a question, which informed the research design, questions and analysis. What influences it has, and whether these are positive or negative, are not assumed, but are explored through the data collected.

Feminist methods are adopted critically, and in practice I actively considered whether the benefits of such an approach, as described here, were realised in my research. As with other research, it is possible for feminist research not to meet its aims, and rather than giving power to the participant may actually regulate them in different ways. Feminist approaches which involve the participant in producing knowledge may 'responsibilise' the participant through creating expectations and demands. Recognising this, I adopted a critical, reflexive approach, questioning the impact of power, motive and intent throughout the process of data collection and analysis, described in section 4.1.3.

4.1.2 Assets-based approach

I adopted an assets-based approach, which understands individuals and groups as possessing positive health- and wellbeing-promoting assets, in contrast to a deficit approach which conceptualises individuals as passive holders of needs and recipients of services (Brooks and Kendall 2013). Adopting this approach allowed the research to explore the role of the individual in meeting and adapting to their own needs. It does more though than simply reversing the traditional deficit model, instead this approach to research allows a foregrounding of what groups and individuals bring to situations, how they adapt to them and how they influence them. For this research, I am looking at an adaptive, dynamic group, in the context of the ageing transition and the background of transition to an HIV identity. In this context, the assets-based approach is most adequate in offering a vehicle to understand the breadth of the individual's experiences.

The need to enhance the evidence base is identified frequently by authors commenting on assets-based approaches (Brooks and Kendall 2013, Friedli 2013). However, other authors point to a growing evidence base, especially at the theoretical level, which is sufficient to support the further exploration of assets-based approaches especially when taken in tandem with the limited impact of alternative approaches (Hopkins and Rippon 2015).

Assets-based approaches allow a wider focus on social determinants of health and on the positive contributions people and communities can make to their own health than deficit models (Brooks and Kendall 2013). Neither approach should be adopted uncritically. An assets-based approach allows a wider focus and engages with communities as agents of change, but risks 'responsibilising' people, placing the onus on individuals to solve problems. It also risks assuming the individual can and should respond to their problems, so that their experiences are reduced to their capacity to respond. Instead, my aim was to explore both the individual's responses, and what supported their capacity to adapt to ageing with HIV, as well as the wider determinants and drivers outside the individual's own actions. The approach was adopted critically, and this wider view maintained.

Assets-based approaches focus on variables that enhance health and wellbeing, and factors that increase quality of life, social capital and resilience (Brooks and Kendall 2013, p.128):

Asset based approaches focus on consideration of capabilities and capacities at the level of the individual, institution, community, social system or population. Although often sub-divided into different domains such as internal and external assets, health assets can be essentially defined as of any factor that enhances the ability to create or sustain health and well-being, such as the resources that promote self-esteem and the coping abilities of individuals and communities.

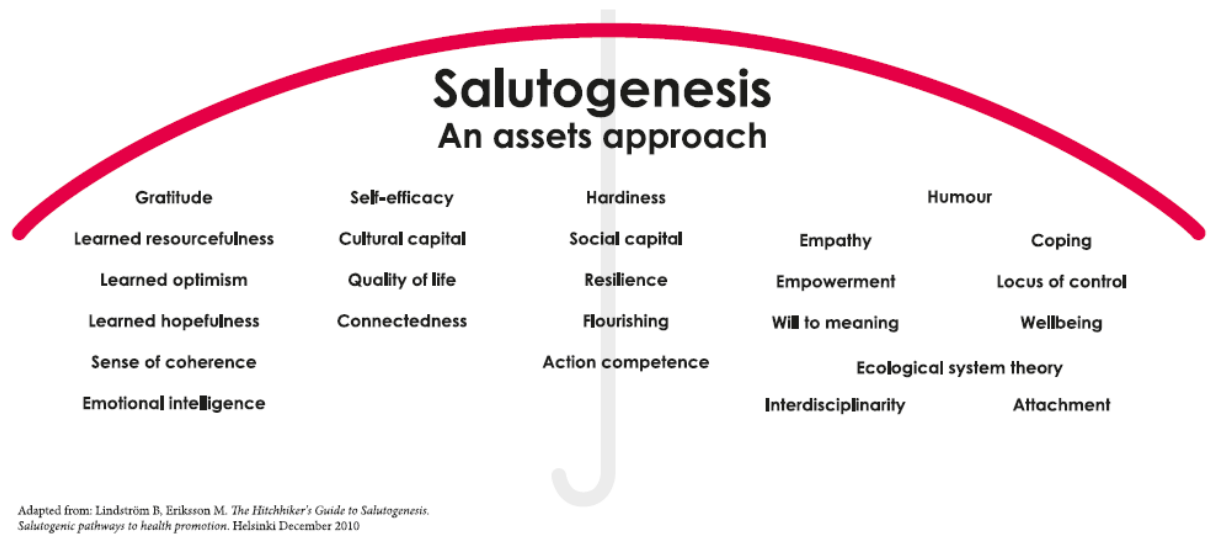
The asset-based model can be seen to comprise of three conceptual strands: salutogenesis and a positive conception of health; health assets; and learning from asset-based community development (Hopkins and Rippon 2015).

'Salutogenesis' is a concept that focuses on what generates health (in contrast to pathogenesis which focuses on the creation of disease). The concept was developed as an alternative to disease-centred models (Antonovsky 1996). The model incorporates health promotion alongside disease prevention, and recognises health as continuum between 'healthy' and 'sick', with the potential for individual action to improve health (Antonovsky 1996).

The salutogenic model is conceived as two sets of factors or properties. The first set, described as 'sense of coherence', refers to an individual's sense of comprehensibility, meaningfulness, and manageability over their life and the challenges they face (Antonovsky 1996, Hopkins and Rippon 2015). The second set, 'generalised resistance resources', refers to resources individuals and communities have that facilitate coping with stressors (Antonovsky 1996). This includes "material and financial wealth, knowledge, intelligence, ego, identity, coping strategies (rational, flexible, far-sighted), social support, commitment (continuance, cohesion, control), cultural stability, cultural norms, belief or faith, religion, philosophy, art, mysticism (a stable set of answers or explanations) and a preventive health orientation" (Hopkins and Rippon 2015).

The following figure outlines a salutogenic model of assets (Hopkins and Rippon 2015, p.15):

Figure 4.1: Salutogenesis: An assets approach, (Hopkins and Rippon 2015)



Key questions include what assets have value, for whom, and within what social contexts, and how health inequalities affect these (Brooks and Kendall 2013). There are further questions around how the individual understands, values, accesses and benefits from their assets, and what confounding factors (such as material deprivation) may limit their scope to gain the benefits of those assets.

In the context of health inequalities between groups, and poorer health for disadvantaged or deprived groups, there continues to be a lack of evidence of what is effective in addressing these differences, in particular due to an over-reliance on deficit-based evidence (Morgan and Ziglio 2007). Consequently, Morgan and Ziglio (2007) present an asset model intended to complement deficit approaches focused on risk, with a focus on actions which promote health, reduce disease, increase self-esteem and reduce dependence. Their model has three elements: drawing on the ‘salutogenesis’ theory to define assets; the concept of asset mapping; and asset indicators.

Health assets can be defined as “social, financial, physical, environmental or human resources”, operating at the individual, community or institutional level (Morgan and Ziglio 2007, p.18). Connections within a community can be a source of assets such as “resilience, access to support, opportunities for participation and added control over their lives” (Hopkins and Rippon 2015, p.12).

Asset mapping is a process by which the assets of a group or community are assessed, prior to an intervention, ensuring the intervention builds on the

strengths they have already (Morgan and Ziglio 2007). Factors that will enhance or contribute to health and wellbeing are ascertained, and this shapes the intervention or activity undertaken. Asset indicators are then developed to assess progress. Approaches to asset-mapping include the 'head, hands and heart' model: "in which participants are asked to respond to three questions: What knowledge do you have? ('head'); What skills do you have? ('hands'); What are you passionate about? ('heart')" (Hopkins and Rippon 2015, p.3).

Overall the asset model conceptualises the community as a co-producer of health, and the individual as an active agent in creating, maintaining and improving their own health and wellbeing. The process of identifying and mapping the assets individuals and communities have supports a respectful and participatory process that ensures the power and influence of the research participants, and acknowledges their own vital role in achieving positive change. In the context of living with a long-term condition, and preparing for old age, an assets-based approach opens up space to understand how individuals and communities cope and adapt, and the resources they already have to sustain and create good health and wellbeing. It does so whilst also opening up discussion about gaps and challenges, which can be addressed positively in a framework of co-production and shared ability.

Adopting an assets-based approach to understanding the assets as well as needs of older women living with HIV, will enable this research to produce findings that are implementable in an assets-based paradigm. More, the adoption of an assets-based research methodology conceptualises research participants as active actors in meeting their own needs, and ensures the research power dynamic is kept in check by avoiding a paradigm of participant as 'in need' and the researcher as 'solving the problem'. Importantly, it allows space to explore both positive and negative experiences, and the focus on assets was implemented carefully to hold space for participants to share problems and negative experiences of exclusion, neglect and misunderstanding.

It is important to note that there are criticisms of assets-based approaches, particularly the risk that a model focussing on the ability of a community to meet its own needs will deflect from holding to account authorities with responsibility to

meet their needs, and undermine the political case to address health inequalities (Friedli 2013). Friedli (2013) argues that the assets-based model over-emphasises psychosocial determinants of health, and fails to account for the systems of power and privilege that create and entrench health inequalities. Her argument, that assets-based approaches could support a neoliberal model of viewing individuals as authors of their own problems and therefore solutions, without addressing the impact of systems of power and material injustice, is persuasive. However, others have disagreed with this analysis, suggesting instead that assets-based approaches offer a means to address inequalities in a way that promotes power within individuals and communities, enhancing solidarity and collective responses (Roy 2017).

It is instructive to be guided by this debate, and consider the extent to which these concerns hold for assets-based research. By adopting both a feminist and assets-based approach, the impact of systems of power, and the causal factors promoting and systematising disadvantage, were kept in view. Together, the two theoretical frameworks support a research approach that both recognises and analyses power, and understands individual potential to adapt, create and promote positive change.

In particular, Friedli (2013) calls for an analysis that recognises systems and institutions of power and acknowledges their limiting impact within a social justice frame. She elucidates this within a historical context of social justice and patient advocacy movements, within which the HIV movement can be seen (though Friedli does not make this connection). The focus on community and participation in this research addressed the limitations Friedli describes, by an original approach that situates assets in a political and social justice framework.

Assets-based models can be misused to promote a neoliberal, individualistic approach to development, characterised by focus on empowerment and individual action. In this application, the individual is cast into the role of entrepreneur, with the self and one's health and social status as a project, with assets available for investment, growth and realisation. This can be seen in, for example, approaches to social mobility that emphasise individual commitment and work as routes to improving socio-economic status, typified by reference to

individual exemplars of difficult backgrounds overcome by hard work and ‘pulling yourself up by your bootstraps’. The challenge here is that view is disassociated from wider contextual and structural factors that lie outside the control of the individual. It is key therefore to ensure that the assets-based model is situated in a broader context – in the case of this research project, with a contextual understanding of the clinical and social implications of ageing with HIV, and the policy and practice environment in which older women living with HIV are situated. These factors will influence both the outcomes for women and the environment in which their assets are realised. This is also critical in applying assets-based approaches to community, rather than individuals. The ‘community’ of people living with HIV or women living with HIV is internally highly diverse, including individuals with little to no access to material resources or social capital as well as others with plenty of both. An assets-mapping of a community has to account for this internal heterogeneity, to avoid the risk of blame or censure attaching to individuals seen not be benefitting from ‘community assets’ that in reality, they have no access to. Structural inequalities and barriers apply within communities as well as to communities, and this was held in view in my analysis.

In terms of research, asset-based approaches have been adopted to move research from a top-down model done ‘to’ or ‘for’ communities, to research done ‘with’ communities. A study in Chicago developed an assets-based model for community involvement in research (Lindau 2011). The model begins with discussions between community and academic partners to elicit shared theoretical perspectives to underpin research. These values, such as empowerment, trust/respect, relevance and leadership, inform a set of principles guiding the research, which include involvement in decision making, building mutual respect and trust, and mutual learning (Lindau 2011). Subsequently, community priorities are identified by community members and researchers through collaborative processes, and then community assets are mapped. The academic partners then carry out research, informed by all the preceding steps and with participation of community members. Sharing of actionable data with community partners, and action to implement findings, conclude the process.

Lessons from this model were transferred to this research. In particular, the process of defining shared research priorities was adopted, through the use of participatory literature review and data analysis.

Studies of assets-based approaches to healthy ageing have indicated the salience of the approach as life expectancy increases, and quality of life in later life requires targeted attention (Cosco, Howse et al. 2017). A systematic review of health assets in older age found good evidence that the following are protective and promotive of good health in older age (Hornby-Turner, Peel et al. 2017, p.11):

... self-rated health, life satisfaction, psychological wellbeing, social resources, engagement in leisure and social activities, education and financial resources...

Drawing on experience of empirical asset-based work with various communities, Russell (2011) argued that engaging older people, recognising and building on their strengths, is essential to promote healthy ageing. The skills, knowledge, and action of people and communities are complementary to services and agencies, and can do more than formal structures could deliver alone (Russell 2011).

Additionally, an assets-based approach which incorporates resilience into models of healthy ageing better accounts for people's experiences, as the ability to cope and adapt with disease and disadvantage is critical to capture given the likelihood of experiencing adversity as people age (Cosco, Howse et al. 2017, p.580):

... an individual that maintains a high level of functioning in the absence of adversity is healthily ageing, whilst one who maintains the same high functioning levels despite having experienced adversity is both resilient and healthily ageing.

Consequently, resilience and understanding both what adversity and disadvantage is faced and how it is faced were considered in my analysis.

4.1.3 Reflexivity

Reflexive practice is increasingly recognised as a vital component of good research, particularly associated with feminist research practices. It formed an especially cogent aspect of this research, which is informed by my own position as researcher and advocate. It is also pertinent in HIV-related research, which is a politicised paradigm informed by activist-led demands for meaningful

involvement. Reflexive practice was an ongoing process as I conducted the research.

Reflexive practice requires the researcher to explicitly position themselves within their research, and to acknowledge the influences of their own views, context, experiences and role in shaping all aspects of the research (Green and Thorogood 2014). Foley presents a history of the emergence and development of reflexivity, within ethnography where it first appeared (Foley 2002). He suggests there are four forms of reflexivity in ethnography: confessional, theoretical, textual and deconstructive. The first of these he associates with feminist research approaches.

Foley (2002) charts his own development as a researcher, motivated by a desire to make academic writing more engaging and accessible, and to situate his work within a political context with his own 'voice'. While Foley's analysis specifically refers to ethnography, his description of reflexivity is useful. In particular, understanding that reflexivity emerged as a response to positivist social science, aiming to undermine the idea of ethnography as 'fact' and to situate the researcher within the research, is instructive, in a participatory research model focused on shared production, the assets of the community and individuals being researched, and a feminist recognition of the need to achieve a balance of power between the researcher and the 'researched'. Understanding and critically examining my role as researcher supported the assets-based, feminist and participatory methodologies adopted, and, as Foley describes, facilitated a greater political positioning of the research.

Similarly, Dean (2017) outlines how reflexivity allows for the essentially political nature of all research to be accounted for, noting that objectivity is impossible: a myth that elides the perspective of the powerful with reason and objectivity. Reflexivity allows for a thoughtful positioning of the researcher and a framework to consider and engage with the researcher's own social categories and positions and how these intersect with the research (Dean 2017). In chapter six of this thesis, I use Dean's framework to provide a reflexive account of my own role and position in this study. Following Dean (2017), I make the case that this is not narcissism or navel-gazing, but an approach that makes the researcher

vulnerable through making them (me) visible. This makes visible a subjectivity that is unavoidable: there is always a researcher, collecting, analysing and presenting data in a way that is inherently subjective. Reflexivity allows this subjectivity to be brought into view and debate, and for the reader to draw their own conclusions (Dean 2017).

Recognising that social scientific research does not, and cannot, paint a picture of the world 'as it is', identifying 'truths', is a core tenet of reflexive research. I would argue it is also an essential aspect of truly participatory and feminist research, inasmuch as such practices aim to redress the implicit power imbalance between researcher and research participant. To contend that the researcher, through data collection and their own interpretation, evaluation, and writing, is able to access and describe the 'truth' of the experiences of others, is to imbue the researcher with significant power. More, by suggesting that the conclusions of the researcher, which may differ significantly from the interpretations of the research participant, are somehow more truthful or valuable by virtue of their position as external observer, is to establish and embed a fundamentally skewed imbalance of power. Both viewpoints are inherently valuable in the research process – the lived experience of the participant and the listening and analysis of the researcher each add an important element to the process of research, and must be accounted for. Reflexivity complicates and enriches both the research encounter itself and the interpretation of the researcher, creating space to engage with the process of research as well as the outcome. The tension between researcher and researched and the question of power is fundamental in research, and is part of the research process itself. Reflexive approaches facilitate a praxis that recognises this, and explores it as a part of the research and as generative of knowledge. This effectively expands the field of study, to include the process of research itself, allowing for a potential increase in critical 'vigour'.

My aim is to recognise myself as researcher and also a *participant* in the research. In the next section I address participatory research practices in detail, but for now it is sufficient to define the participatory model as one in which participants are involved in all stages of the research, including defining the research questions and the analysis of the research data. Their role is not to

simply 'be researched' in a passive sense, but to be actively engaged in and hold ownership over the research as a whole.

Each of these presents challenges – the process of conducting reflexive research demands more, I think, from the researcher, in terms of both emotional input and honesty about challenges and failings. It also asks more of the participant – casting participants as co-producers creates a role that may not be what they sought when they signed up for a workshop or interview, especially if they have prior experience of taking part in research that did not adopt this approach. It was therefore critical in recruitment to describe the participatory nature of the research and what was expected of participants accurately and accessibly, but even so the approach assumes participants will wish to be engaged in knowledge generation in addition to sharing their own experiences.

There is, of course, a huge potential gulf between principles of methodology and methods in practice. In the course of doing research, I may lose sight of the tenets of feminist practice, and exercise more influence, where this is available to me. Reflexive practice is in effect a 'check and balance' in this process, by creating a framework in which as the researcher I regularly took a step back from analysing the data to also analyse myself in that data and ask: how has my involvement shaped it, how has my own experience or personality influenced how I am interpreting it? For this reason, data analysis informed by reflexivity is more adequate because it acknowledges that the priorities, views, beliefs and experiences of the researcher influence what is asked, seen and understood.

Reflexivity can be a tool supporting the researcher to engage with questions such as why they want to do research, how to carry it out and their relationship with the community or group in which they carry out that research (Stevenson, Keogh et al. 2018). The extent to which they individually belong to that group, and why they feel this sense of belonging, and how the research process will both be influenced by this and influence it, are all productive questions to engage with.

My first reflexive step as a researcher in this project is necessarily to address my position as researcher, and my commitment to reflexivity in the project. Why is it important that I remain aware of myself, my aims, experiences and priorities as a researcher? This speaks to my motivations in pursuing this research. I have

worked on HIV for a number of years, for a range of organisations in staff, volunteer and trustee roles. My professional life is rooted in the HIV response, and in that sense this PhD is a continuation and deepening of my professional self. I therefore have a wide professional interest in successfully completing this PhD and reaching conclusions that will have some interest or impact in the field. Reflexively, I recognise this may influence the way I pursue the research, and engaging with this was essential to ensuring that this influence was both proportionate and positive. Seeking impact can be positive in ensuring research is ambitious and follows the interesting findings rather than the easy route to completion, but can also represent a simplification or deviation from the research itself. However, if participants are leading the research in a direction likely to be less impactful, there will be tension between competing priorities – participatory and impactful outcomes may not overlap. Addressing and resolving such tensions was a key element of the reflexive process.

In addition to this professional investment is one that is more foundational. An important aspect of my identity as an individual is understanding myself as an advocate, an activist and an ally. The first refers to acting to raise issues, to find evidence and to make change. As an activist, I refuse to accept the status quo and *act* to demand change. Each of these means I have a primary interest in identifying the challenges in people's experiences and in particular where the 'system' is failing. Being aware of this focus in my analysis was essential in mediating my analysis and reflecting on what I prioritised.

This conception of myself is vital for my own interest and commitment to the work that I do, and also has meaning in a wider sense. Many people working in HIV are themselves living with the virus, or belong to a community disproportionately affected by it. This, and the tradition of involvement and participation associated with HIV, gives significant currency to questions of motivation – why are you doing this work? It is a question I have been asked many times – by research participants, colleagues, supervisors and more. Why do I do this? Motivation and affect are questioned, and often linked to authenticity. In many ways, advocates are understood like superheroes – they seek to save the world, and they have origin stories that explain why. For people living with HIV, or gay men, for example, in many cases the motivation and origin of their advocacy is assumed

– of course they want to effect change in HIV, as it affects them directly. For a white, heterosexual woman not living with HIV, the ‘origin story’ is less clear, and so more questioned.

This is an interesting process, not least in the assumption that belonging to a community is sufficient to inspire advocacy for the rights of that community, and in what experiences are sufficient to inspire. Individual motivation does not always make for a good origin story. It is messy, incomplete, difficult, and sometimes even unconvincing. Experiences of illness and of violence led me to this work, alongside more prosaic factors such as chance encounters and professional interests. Even for people who are living with HIV, their route into ‘the work’ is often conflicted and unclear. These questions all, I suggest, link to how community is formed, and delineated. If you lack the right features for automatic entry, you have to prove your value and commitment to ‘get in’. This reminds me of the interview process for my first job – working in community engagement for an African organisation. I applied (my first ever proper application) as practice, really – I assumed the role would be given to an African person. I was surprised, then, when I was offered the position. Later, the CEO confided that he had also been surprised. My first name is quite common in African countries with British colonial histories, and he had assumed the woman coming to interview was of African origin. That mistake got me through the door, where I scored highest in the interview process and therefore got the role.

That sense that my position or role is based on merit (and perhaps privilege) but lacking authenticity is one I have experienced throughout my career. It has rarely been a suggestion made by others, but speaks more of my own personal fears. Placing my role and my right to be there in dialogue has contributed to my development of a reflexive praxis, and has, I believe, improved my work. I worked with that first organisation for four years, eventually as Acting CEO. Recently I bumped into the head of a partner organisation I worked with in that time, who in the early days had questioned whether I could do the work properly as a white, British person. In that conversation, he referred to me as a ‘powerful African woman’ and said that he hoped I would return. So sometimes outcome can overcome origin.

The question of who the individual is also relates to how advocacy is done. In my case, I have never been the 'loud advocate'. As a teenager, I was involved in advocacy activities with Amnesty International. During the run up to the Iraq war, I organised candlelit vigils, letter writing and petitions. Others went on a 'school strike' and occupied the yard at the front of the building. That still quite neatly summarises the form of advocacy I enact. I once became involved with ACT UP London, an HIV advocacy group. The convenor of the group once super-glued himself to Gordon Brown (BBC News 2008). My major contribution to the group has been drafting an open letter and seeking signatures from politicians and the public (Strudwick 2015).

These experiences have led me to engage with the final aspect of identity I listed above, 'ally', which is perhaps the most critical but least widely recognised. The concept seems to have emerged within the sex workers rights and anti-racism movements, and has a largely online profile. In a blog, a sex worker writing under the name "eithnecrow", describes the importance of giving primacy of voice and platform to people who belong to the community being discussed, in the context of a sex work-focused conference she had attended which gave little space for sex workers to describe their own realities ('eithnecrow' 2014, no page number):

It was, not for the first time, a case of marginalised people becoming objects of enquiry for others, and it made me think that it might be time for a broader discussion about how this sort of stuff happens, and what kind of invisible power dynamics allow it to go largely unchallenged. When this happens, we – as people interested in social justice and the dismantling of systems of oppression – have a problem. The existing hierarchies that dictate who should do the speaking and who should be spoken about are reinforced and reproduced.

The writer uses this experience to call for a more considered positioning of people from outside the sex worker community who through their professional or other position are given a platform to speak *about* sex workers, regardless of whether their intentions are positive. This is powerfully described as an ethical need "that when someone builds their career on the disenfranchisement (read: suffering) of others, their gains must be counterbalanced with equivalent (or ideally, greater) benefits to that community" ('eithnecrow' 2014). This acknowledgment is at the core of being an ally – recognising your own power and seeking in practice to

meaningfully promote the voice and interests of those you research over your own personal advantage.

It should also be recognised that in statements such as that above, other forms of power are being exerted. By both undermining the right to a voice or platform of those classed as 'outsiders', and demanding equivalent or greater benefits to accrue from the outsiders' work, 'ethnecrow' is also wielding power. This form of identity-based power can work to silence people who do not belong to a particular group – but who defines that group and who belongs to it can also be contested, and is subject to the power of voices within that community. In these activist contexts, being perceived to have power can actually be disempowering, even silencing. More, individuals who do not share an identity may yet have valuable contributions to make, based on their expertise, work, or other aspects of shared experience. It would be inappropriate, for example, for me to speak on behalf of older women living with HIV, or take up a platform and silence the voices of older women living with HIV. But it would not be inappropriate for me to present the findings of my research.

There is an element of identity politics at play here, which can confound expertise with experience. Having experience of something does not necessarily connote expertise in it, any more than lacking an experience suggests you have nothing useful to contribute to a discussion. An example of this involves the musician Chrissie Hynde, who spoke in a newspaper interview about her experience of sexual assault, suggesting it was her own fault, and that women who dressed in certain ways or chose to be alone with men could expect no different (Murison 2015). As one commentator noted (Cosslett 2015, no page number):

The dawn of identity politics has led to a kind of individualism where having experience of something confers a special status, an assumed expertise. But just because Hynde was sexually assaulted doesn't mean that she is an expert on sexual assault, on what causes it and on how it should be tackled.

Expertise can be built and acquired in different ways. Lived experience is a form of expertise but not the only kind, and nor is it complete. It can also be more or less powerful given how relevant the experience is and how it is deployed.

The question of 'career-building' is also a vital one. That language is in itself an exercise of power – it suggests selfish motives, a malign intent. The professionalisation of the HIV sector is often discussed negatively by activists. It is important to be aware of this, but professional development, career and salary are not in themselves negative goals or attributes. Many of the professionals who shape the HIV response are themselves living with HIV or from communities affected by HIV. Others have specialist skills, knowledge or training and make a positive contribution. There is a balance to be found, and this is part of being an effective ally: recognising the legitimacy of my own work, while also seeking to be involved appropriately. Rather than a simple distinction between professional and activist, erecting a dichotomy that people on either side can easily fall foul of, and failing to account for people who occupy both roles (for example HIV charity CEOs who are themselves living with HIV), it is more useful to consider the social, cultural and other forms of capital that shape access to and participation in this field. Some activists, and some professionals, have education, wealth and social capital, others have none. These distinctions are more fruitful to reflect on.

This is all relevant to my own practice as an activist, a professional advocate and a researcher. My focus is on HIV, gender, marginalised communities and gender inequality. I am not living with HIV, I am a white, cisgender woman, I identify as heterosexual, and I have the advantages of education and opportunities. As a woman, I am subject to gender inequality, and I have experience of gender-based violence. In short, in terms of my professional work, I am mostly an outsider, pursuing a career focused on the experiences of others, but informed by shared experiences particularly defined by gender. Being an ally in this context means recognising and remaining aware of this. Understanding the power I have and ensuring I do not exploit it, while recognising the expertise of individuals and communities in explaining, understanding and defining their own experiences. In my professional practice, this is core to what I do. In the context of this research, reflexivity helped ensure this permeated each stage of activity, and that it was an ongoing challenge posed to what I do and how I do it. The additional value of reflexivity in this context is its ongoing nature, as feminist activist @FeministGriote wrote on Twitter, "Being an ally is a process not an identity."

As an advocate, I am part of a wider community of or around HIV, although I do not belong to the community of people living with HIV. I share many aspects of identity with my research participants, including gender, and potentially also class, education, ethnicity, and sexuality. No one is defined wholly by one aspect of their identity, and our experiences are shaped by all aspects of our identity. Dean (2017) argues that the insider or outsider status of research and researchers should be seen as a spectrum, instead of a dichotomy (p.137):

Drawing lines about who is allowed to research what community is a dead end, because of the personal vagaries and multifaceted identities we all have. While clearly both insider and outsider perspectives have assets and liabilities, automatically privileging one to exclude the other is damaging and limiting, especially if such reasoning is done before any analysis of research quality.

It is also important to consider, in responding to 'ethnecrow' and similar suggestions, that there can be an interesting role and function for the 'other' in conducting research. When participants view the researcher as 'other', whether due to background or experience, they can be more likely to articulate what might otherwise be assumed: to state and explain elements of their experience in different or more detailed ways than they might with someone who is considered to be 'more like them'.

In addition, reflexivity creates a framework to engage in thinking about why I am doing research and why participants take part in it, and to what end. Why research is done and for whom is necessarily power-laden. In conducting this research, my aim was to collect and present the experiences of older women living with HIV, to make their experiences visible and to seek to influence practice in relation to them. Similarly, participants might seek to share their experiences with a view to becoming more visible, having their needs recognised, and in turn, met (or have quite different motivations). In doing this, there are risks of negative outcomes. The research findings may, through suggesting a lack of need, lead to a reduction in attention or service provision. Or the findings may be misused, to foster stigma or negatively impact on women or other people/groups. As with all research, limited by time, resources and ability, the findings will be a construction. Yet research such as this is necessary to telling the story of people's experiences and influencing change, whether in policy or practice. It is imperfect but essential.

Reflexivity also supports managing my two distinct roles, as researcher and as advocate, and in addressing challenges that may arise from simultaneously holding them. Hiller and Vears (2016) argue that reflexivity can support clinician-researchers to overcome challenges in conducting qualitative healthcare-related research, such as struggling to set aside their health professional role and participants misunderstanding the benefits of participating. The advocate-researcher may, I suggest, face similar challenges. The participant may expect individual support and advice, or for your findings to definitely influence policy and practice. As an advocate, you enter the research process with a politicised outlook and strong opinions around the need and potential for change. Both can lead to bias in the research process, and the former can affect informed consent. Reflexive practice can support addressing these challenges, by creating a framework for the researcher to engage with their own motivations and critically assess where and how these are influencing their research practice (Hiller and Vears 2016). For participants, reflexive practice can promote the researcher thinking critically about how to recruit, what information to share, how to describe their own role, qualifications and motivations and to present the research project, as well as its potential outcomes, ensuring participants are fully informed (Hiller and Vears 2016).

In addition to those already discussed, Foley identifies a further benefit to reflexive approaches, in promoting a more engaging and accessible writing style (Foley 2002). Reflexive research is rooted in an experiential way of knowing, with richer, more emotional and more situated language, enhanced with personal stories and an embodied authorial voice. When done well, Foley argues, this addresses power imbalances in research and facilitates greater 'readability' of the research publication(s). For Foley (2002), this involves adopting a personal voice, including relevant personal and historical events and interactions with participants, and utilising humour, tone and dialect, to explicitly position himself in his academic work. How a text is written, engaging with the reader, the voice of the writer, and creativity are all as important in academic as in other types of writing (Mitchell and Clark 2018). Writing in an accessible, engaging way enables research in the social sciences to achieve its purpose (Dean 2017, p.151):

The point of research is not to promote oneself narcissistically, or to further oneself – it is to gather and provide information which others may find interesting or useful. If that information is poorly communicated, in an inaccessible language which hides it from multiple audiences, the research is incomplete.

I will consequently seek to adopt a more accessible style to allow more people to engage in the outcomes of the research. In particular, I see ensuring that participants in the research are able to access the outputs of the research – to potentially read the text and understand it, see their own views and voices within it, and lead their own dissemination or other activities as co-owners of the research - as essential to ensuring that my research practice is participatory.

Reflexivity can also support ethical research practice and addressing ethical tensions, which are vital to research, both in research design ('procedural ethics') and in carrying out research ('ethics in practice') (Guillemin and Gillam 2004). Procedural ethics, such as seeking approval from research ethics committees, are described as necessary but insufficient steps towards achieving ethical research (Guillemin and Gillam 2004). In practice, the ethical issues that arise for researchers will likely differ from those addressed in formal applications, and can be hard to predict. The ethical implications are also wide – for example, in the case of a disclosure of a criminal issue, the obvious ethical question is of confidentiality: whether the researcher should breach it in order to involve the police. But beyond this, Guillemin and Gillam (2004) describe immediate issues, such as whether the researcher should continue the interview, should respond verbally to the disclosure, and if so, how to do so, whether the recording of the interview should continue or be stopped. The nature of unpredictable 'ethically important moments' in research is such that procedural ethics cannot adequately account for them.

However, the authors argue there is in fact continuity between procedural ethics and 'ethics in practice', and reflexivity accounts for and extends procedural ethics into practice. The former claim is made based on an identification of shared values between procedural and practical ethics, such as informed consent and respect for the autonomy of the individual. As such, the procedural model provides a framework to address ethical tensions, and creates an environment in which these are recognised in practice.

This is not, however, a model for dealing with ethical issues as they arise. For this purpose, the authors make the claim, following Bourdieu, for the role of reflexivity in actively scrutinising the role, actions and interpretations of the researcher (Guillemin and Gillam 2004). They argue that reflexivity is connected to ethical practice, as an ongoing critical process that assesses the research methods, motivation of the researcher, ultimate purpose of the research, and interactions between the researcher and participant(s). This critical attentiveness includes awareness of ethical issues throughout the study, and thinking over potential issues and responses, supplemented with ongoing awareness of the impact of the research on the participant.

Guillemin and Gillam's assertion that reflexive practice will encourage the researcher to critically engage with potential ethical issues, and so be better-prepared to deal with them, is not fully convincing, as the same claim could really be made for procedural ethics. However, it does seem to be realistic to suggest that practice that explicitly and continuously considers and prioritises the impact of the research on the research participant should enable more ethical practice. Expanding reflexive practice to include ethical considerations therefore seems a persuasive proposal.

Reflexivity will also provide a potential means of maintaining safety and mitigating negative impact on the researcher through feminist practice. Based on the findings of a broad inquiry Sampson, Bloor et al. (2008) conclude there is a significant emotional cost associated with feminist research. They argue that this emotional cost is linked to prioritising reflexivity, research relationships and power dynamics, and concern with the needs and interests of the participants, (Sampson, Bloor et al. 2008). This informed the reflexive underpinning of this research project, where the needs and interests of the participants were prioritised, but with an understanding of potential impact on the researcher.

Finally, reflexive feminist research speaks to my identity and priority as an 'activist researcher' (Cameron 2005, p.490):

It is worth pointing out here that any kind of politically committed approach to social scientific research must build in the kind of reflexivity that can lead to paradigm shifts. The goal of political activity (including politically committed research) is to change the world: to

the extent that goal is achieved, it will be bound to change the research agenda too, as changed social conditions present new political challenges.

4.1.4 Participatory methods

Building on the feminist, assets-based and reflexive methodologies explored in this literature review, and adopted in this research, it is inevitable that the methods adopted will be influenced by participatory practice. The methods used are outlined in detail in section 4.2, but the literature underpinning them is briefly explored here.

Firstly, this project uses qualitative methods. A qualitative approach is taken due to the nature of the subject matter being explored, as it is poorly-understood, deeply rooted, complex, delicate and sensitive (Ritchie 2003). The experiences, needs and communities of older women living with HIV are best explored through biographical methods which give participants scope to describe and define their experiences.

There are many definitions of qualitative research, but as Kvale has suggested (Kvale 2007, p.viii):

Common to such approaches is that they seek to unpick how people construct the world around them, what they are doing, or what is happening to them in terms that are meaningful and offer rich insight.

Key features include concepts being developed and refined through the research process, rather than established and then 'tested', and that the methods and theories used should be appropriate to the specific study. Context and the researcher themselves are identified as important parts of the research process. Green and Thorogood (2014) have argued that because qualitative research is characterised by a rejection of uncritical positivism, and an adoption of reflexivity and flexible research design, it is the best approach to answer questions on the experiences, perspectives or meanings of participants. This has led to the increasing use of qualitative methods in health research, looking at both health and illness within the context of individual lives. Ritchie further defines four features of effective qualitative research (Ritchie 2003):

Contextual: descriptive and exploratory, how participants experience the social world.

Explanatory: the influences, motivations, origins or formations of the subject matter.

Evaluative: exploring how things work and assessing impact.

Generative: creating new ideas to development of social theory.

In this research, I aimed to understand women's experiences of ageing with HIV, how they explain and define their experiences, whether existing social support and formal networks satisfy their changing and emerging needs, and to suggest ideas to better understand and meet the needs of older women living with HIV. Using an iterative, multi-phase research design to draw out and focus on different elements at different stages, I aimed to satisfy all four elements Ritchie describes. There are broader theoretical elements to this research, too, which go beyond the applied construction Ritchie offers. These elements are layered on top of the applied research within this project.

One challenge in this area is the potentially 'sensitive' nature of some of the issues which will be discussed. Lee (1993) highlights the need to address potential sensitivity in the research topic at each stage including forming the research question, conducting the research and disseminating the findings. He defines sensitive topics as those in which participation in the research poses significant risks (to the researcher and/or the participants), whether due to it being intrusive in nature, focussing on 'deviance' of some form, or due to the political power it challenges (Lee 1993).

This research may be seen to fall under the first two of these categories, wherein the participants will be exploring private and potentially difficult issues, under the subject area of HIV, which is a stigmatised condition within a wider social context. Lee (1993) highlights however that the actual sensitivity of a given topic is highly dependent on the specific questions, participants and context. In this research the population of older women living with HIV is not a 'deviant' or hidden one, and there are good data available on the size and make-up of it. Further, there are numerous proven routes into the community, including through peer and charitable organisations.

Given my professional background and networks, I have the benefit of known links with key individuals or potential 'gatekeepers' such as leading activists and support workers, which helped allay some of the potential concerns of participants regarding taking part. Further, not belonging to the immediate geographic, ethnic, or social networks of the individual participants may have helped reassure them of the confidentiality of the research.

The exploration of sensitive issues within an interview situation requires thought to be given, Lee (1993) argues, to how the topic is approached, the emotions at play in the interview, the power dynamic and the interview conditions. Each of these elements will be addressed in the discussion of the life story interview methods which shortly follows.

In common with the feminist and assets-based theoretical framework, the research will use participatory methods and practices as far as possible. Participatory approaches aim to transfer greater power to the research participants, and situate the researcher and participant on a more equal footing. Participatory methods acknowledge the subjectivity of the researcher and address the power imbalance in positivist research approaches (Green and Thorogood 2014).

The principle of participation in research and of a meaningful and influential role for people living with HIV throughout, has a strong history in HIV related research. In clinical research, this has resulted in the development of Community Advisory Boards (CABs). CABs offer a model to engage communities in developing and monitoring research and to promote informed consent and meaningful involvement (Quinn 2004). Specifically, they can help to avoid lapses in informed consent, where participants are not fully aware of the potential implications of their involvement in the research, by acting as liaison between researcher and community (Strauss, Sengupta et al. 2001). Lapses include lack of voluntary participation (e.g. where the participant feels pressured to take part), incomplete disclosure (e.g. of possible consequences of participation) and confusion around terminology used in the research.

While the role of the CAB in social science research is less established and understood, it is emerging as a good practice model – often with representatives

sitting on research steering groups. In the UK, the UK-CAB acts at a national level and has almost 700 members, including both people living with HIV and allies (including myself). The UK-CAB is led by a steering group, and members vote for representatives to join the research advisory groups of research projects.

The range of roles community representatives take in research has grown and continues to expand, from providing insights as part of a CAB, to active research co-production as well as participating in data collection. Such innovations in participatory methods have ethical implications, though it is suggested that the link is under-researched (Nind, Wiles et al. 2013).

One example is the model of 'inclusive research', based on research with people with learning disabilities (Nind and Vinha 2013). The authors used inclusive research practices, such as reflective thinking phases within group workshops, research newsletters and illustrated summaries to cross-pollinate between groups, and final groups to review the findings from the process. The process echoes many of the calls for participation made by people living with HIV, including the need to acknowledge power dynamics, and be mindful of who originates ideas, leads and makes decisions. The review highlighted benefits for the participant researchers, for the quality and depth of data collected and to the wider community of people with learning disabilities.

Participation in data analysis has though, Nind argues, been much less undertaken and explored (Nind 2011). The case for inclusion to extend to analysis of the data is clear in emancipatory research, however, as the question of who produces knowledge and how is central.

The literature on participation in research highlights particular challenges, such as including people in each stage of research, and ensuring effective involvement. From my own experience, there can be further challenges, specifically around who participates and who they represent. In particular, where research or other activities are perceived as requiring skill, knowledge or experience, participation can become exclusive, and can fall repeatedly to those who have already gained and demonstrated experience.

In terms of research, a perceived need for experience can lead to individuals being sought out for their research experience rather than their personal

experience, which raises questions over representation. By adopting a staged approach, I recruited women living with HIV who have professional insight and experience into key stakeholder interviews and those with research experience to participate in data analysis and literature review. The life story interviews and workshops, alternatively, explored personal experiences and narratives, and included women who are not 'usual' or experienced research participants.

Participatory research can be empowering, but this is only possible through intentional design and practice. Without this, when people as individuals or a group become 'othered' as objects of study or recipients of services, they can become detached from their own expertise *vis-à-vis* their lived experiences. Within research, power wielded unreflexively can disempower the research participant and transfer and solidify expertise and authority in the researcher. Recognising the potential for participation to disempower, I sought to actively and critically engage throughout this study to support an effective transfer and diffusion of power through use of participatory methods.

In turn, this creates a responsibility to prioritise research impact and effective dissemination such that the findings might positively influence the lives of older women living with HIV. This a familiar paradigm for me to operate in, as most research I have conducted has been carried out within a civil society environment, working with community members to produce research with explicit aims to improve some aspects of their lives. It is less usual, perhaps, in an academic research environment working towards a qualification. Whether or not I am awarded a PhD will not depend on whether my research findings have influenced change, only that they are novel. But novel findings can languish on a library shelf alongside the mundane. The measures of success externally placed on this research therefore differs from those I am used to. Nonetheless, there is no necessary tension between the two. By developing the research with the community I am researching, their priorities were centred, leading to greater potential impact in their lives, while the originality of the findings will be enhanced by exploring under-addressed issues and experiences. Good research as defined by the terms of the feminist approach I adopt is both more likely to achieve an academic qualification and more likely to achieve an impact. It is my hope that using participatory methods will enhance the likelihood of both outcomes.

Consequently, the research was carried out in phases, with participatory methods built into to each stage. Firstly, in the empirical review, I involved women living with HIV with research experience in a discussion of the findings of the review, to further identify gaps and share their own experiences of any differences between their priorities and those taken forward in empirical studies.

In participatory workshops, women living with HIV had the opportunity to define their own priority issues, influence the research design, and shape the research questions. This was followed by interviews with key stakeholders, including women living with HIV with a professional or other non-personal insight into the needs of older women living with HIV, among others such as researchers and clinicians, supplemented by a review of HIV policy.

The final method used is life story interviews with older women living with HIV. The interview is a core method in qualitative research: a defined interaction with a purpose demarcated by the researcher, who adopts a questioning and listening approach to obtain knowledge (Kvale 2007). Interviews provide a space to explore the experiences of the participant. Kvale (2007) defines two conceptions of the interview process and the knowledge it produces. In the first, the interviewer is conceived as a 'miner', seeking to unearth and extract hidden knowledge. The second casts the interviewer as a 'traveller', exploring an unknown landscape and gathering experiences through travelling with the participant. This second aligns with the feminist and reflexive approach taken here, and therefore suggests the interviews should be co-produced, adaptive, and be combined and concurrent with analysis so the road is mapped as the journey is travelled.

As well as a 'traveller', my aim in this research, and in using the life story method, is to gather and tell stories. I suggest the role of the researcher is not to just gather or aggregate data, or edit or theorise for 'truth' but instead to function as a storyteller. The role of story in human interaction and social structure is primary and primal. It is the fundamental method by which we all seek to know and understand others, and in so doing to better understand ourselves, our societies and the forces within them. While not simple, and subject to requirements such

as coherence and plausibility which may be limiting, stories are accessible and recognisable to everyone. It is a particularly feminist approach to research.

Brené Brown, research professor at the University of Houston, studies vulnerability, courage, authenticity and shame, and presented a TEDtalk which has been viewed 23 million times (Brown 2010). In her talk, she describes the power of vulnerability and of opening yourself up as a researcher, to be guided by what you find rather than what you sought. She describes her own journey, from a position of 'what counts can be counted' to embracing the possibilities and values of qualitative research, asking "maybe stories are just data with a soul?" This is foundational to my approach to research.

Qualitative research is often devalued by contrasting it with quantitative research, which is seen as formal, academic, measured, measurable, generalisable, repeatable and objective. This oppositional construction not only fails to recognise the research objectives that only qualitative approaches can achieve, but also overestimates what quantitative approaches can do. I would argue that no research can be truly objective. In all research, decisions are made about what to research, how to approach it, who to involve and what to include. Factors including personal interests, career trajectories, funding priorities, professional standing and political position are all in play. It is an old argument, for example, amongst feminist campaigners and advocates on HIV, that the lack of data disaggregated by sex and gender is an impediment to understanding and improving the experiences of women living with HIV. The decision not to collect or disaggregate data by gender is political, individual and subjective, not an objective feature of quantitative research. What is counted is defined not just by what *can* be counted, but by who is counting and why.

As a researcher, my work is underpinned by a belief in the value and power of stories, in defining who we are, how we live and how things can change. This is rooted in a feminist research tradition, effectively summarised by Sarojini Nadar in an article which takes its title from the Brené Brown quote previously mentioned, "stories are data with soul" (Nadar 2014). In this piece, Nadar argues that story and narrative ways of knowing are at the least complementary to quantitative research and have integral value. Her article grew out of a request to

speak at a 'women in research' conference which led her to question how conservative voices shape discourse and define where and how voices are heard. She saw the role of 'women in research' as to challenge the gendered structural inequalities in the academy and question conservative and patriarchal forces shaping how research is valued. In this, she turned to feminist epistemology, especially black feminist epistemology, summarised as an epistemology which values the process as well as the product of research, views the identity of the researcher as being as important as the participants' and seeks to place a human face on knowledge generation, particularly through narrative research (Nadar 2014, p.21):

Feminists boldly declare that story is a legitimate and scientific part of research – the telling of stories, the listening to stories, the construction of stories in a narrative in order to represent research findings – all of these processes are counted as legitimate components of the research process and an essential part of feminist epistemology.

Nadar argues that story is an “epistemological value of feminist thinking” and questions the claims to science and objectivity made by other approaches. They allow multiple ways of knowing and experiences to be surfaced, and in a qualitative study, that is imperative. Feminist epistemological approaches seek to disrupt and interrogate claims to objectivity, not to claim equal value for qualitative approaches but to redefine what is valued and why. She summarises the ways in which narrative research improves and redefines general research practice with the value of STORY (Nadar 2014, p.23):

Suspicion of master narratives of knowledge
Tool of knowledge gathering as well as knowledge sharing
Objecting to objectivity by privileging subjectivity
Reflexive of our positioning as researchers
Yearning for and working for change

Taken collectively, these elements support an approach to research that seeks to understand the complexities of experiences and meanings in participants' lives through research that is participatory, respectful, and seeks to create change.

Feminist and life-course approaches have also been identified as important to research on ageing and gender, as they allow the experiences of women throughout their lives to be explored and the impact of these experiences on their

older age to be understood (Bernard, Phillips et al. 2000). This further supports my adoption of this approach.

Narrative approaches will not be adopted uncritically, however, as I recognise the risk that they can overstate the explainable and understandable elements of experience, I will also engage with what is left out of the stories that are told. Experience is greater, messier and more varied than a traditional narrative can capture, but I suggest that stories get closer to capturing experience than a survey or structured interview, where the questions are pre-determined.

It is in the construction and telling of narratives that the depth and breadth of human experience really emerges. The experience of living with HIV is medical, emotional and social, and as such, a narrative approach allows the exploration of this in the round. It creates space to explore and consider different drivers and causal directions to understand where and how HIV is relevant in the experience of being an older woman with HIV, and how ageing changes, or doesn't, the experience of being a woman with HIV. It brings together the personal, political, individual and social spheres (Woodward 2015). This approach can be seen in the work of Corinne Squire, who explored the 'three-letter lives' of participants living with HIV in the age of ARVs, and describes how despite the increasing 'naturalisation' of HIV through normalisation, marketisation and medicalisation, the challenges of living with HIV continue, due to a range of factors including socio-economic challenges, co-morbidities, disclosure and austerity as well as feelings and beliefs (Squire 2013). Uncertainty, and the gaps between a medicalised understanding of HIV and the lived experiences of people struggling to access or adhere to treatment, care and support, can be explored by adopting a narrative approach.

More, Squire (2013) suggests, drawing on interviews with people living with HIV in the UK, that the process of medicalisation seems to shut down spaces and opportunities to talk about HIV in other ways, and to find appropriate support. For example, psychosocial issues, other than mental health conditions, have become challenging to even discuss, for Squire's participants. They described feeling 'left behind' with symptoms and experiences that did not fit the dominant picture of living well with HIV. In their experiences, they account for medical

progress, but their personal trajectories are far more nuanced, complex and multi-directional. Squire observed a division in experiences between “treatment generations” and a sense that earlier generations felt left behind not just in their experiences not fitting the dominant model but in the loss of space and recognition for the complexity bound up in their survival. For the ‘earlier’ generation, their accounts of health reflected uncertainty, underlying and ongoing fatigue and an ‘up and down’ in physical health (Squire 2013). Narrative methods are most adequate to explore such conflicting, uncertain experiences, creating space for participants to construct their own understandings which may be highly nuanced and change over time.

4.2 Methods and study design

The first step in designing the research is selecting the research questions (Lewis 2003). Drawing on the literature reviews presented in chapters two and three, the question this study seeks to answer is:

What are the experiences of women ageing with HIV in London? How are these experiences understood and expressed?

With further sub-questions:

- How are these experiences mediated by gender, sexuality, ethnicity, migration status and experiences, or other factors?
- How have women adapted to ageing with HIV, including experiences of age-related conditions and other co-morbidities, home and residential care, and economic and social issues?
- What assets do women hold and use to mediate their experiences, and in what ways are they used? Is the notion(s) of ‘community’ amongst these assets?
- How is the concept of ‘community’ relevant? What constructions of ‘community’ can we discern in the experiences, accounts given and discourses employed by older women living with HIV?

- How have collectivities of older women living with HIV, and others, responded to growing older with HIV, for example, through peer support and activism? Does this suggest a 'biomedical citizenship' and how might this function?

Based on these questions, I adopted the following methods.

4.2.1 Research design

The research is structured in phases, in line with the reflexive and feminist approach to research I am adopting. The process is not linear but instead is an ongoing, messy process with each phase of data collection overlapping, and informing the conduct of the following phases, as well as the analysis of previous phases. Methods used are: participatory literature review; participatory creative workshops; stakeholder interviews; life story interviews; and a participatory analysis workshop.

4.2.2 Methods

The first participatory stage, presented in chapter two, included older women living with HIV with experience as community representatives in HIV and ageing clinical studies, to explore and reflect on the conclusions of a systematically-appraised review of the existing evidence base. This upholds the 's' and 'o' of the STORY approach to feminist epistemological knowledge creation: suspicion and questioning of 'master narratives' and objecting to objectivity (Nadar 2014). These, along with a commitment to gathering and telling stories, a reflexive approach, and seeking to influence positive change (the remaining elements) will continue to be practised throughout this research.

Detail on participant demographics and reflections on the process of data collection through subsequent methods are presented in chapter six. Here, I offer an overview of the methods used in each phase of this study.

The first phase of data collection was **participatory workshops**, which included a range of icebreaking and group activities, discussions on various topics using focus group methodologies, and a creative exercise drawing on an adaptation of the 'body mapping' technique. The workshop plan is included at Appendix 5. Body mapping was developed in the HIV context by Jane Solomon, working with the

Bambanani support group, in Cape Town, South Africa amongst others, and is outlined in a manual titled 'Living with X' (Solomon and Morgan 2007). For this research I drew on that manual, as well as personal communications with Nondumiso Hlwele from Bambanani, to adapt the body mapping technique. In a call, Hlwele provided insights into her own experiences as both a facilitator and a participant in body mapping workshops, and advised that whilst the full technique is a multi-day workshop, she felt it would be possible to adapt the methodology to use only some of the activities in a shorter time frame (personal communication, phone call, 7th March 2016).

Body mapping grew out of memory box and similar methodologies – where people with AIDS were supported to use crafts and creativity to explore their feelings and emotions whilst creating a lasting memento, often for children or other relatives (Solomon and Morgan 2007). As treatment became available, and people diagnosed with HIV were no longer being prepared to die but supported to live, body mapping was developed to replace memory boxes, as a tool to explore feelings about the future, hopes and dreams, and adapting to live with HIV. Participants are led through a series of activities, over a five day workshop, exploring their feelings and experiences about HIV. This can be used, the authors suggest, as a therapeutic tool, for healing, for gathering and telling life stories, and also as a research tool (Solomon and Morgan 2007, p.3):

... body maps can be used in research. They work well as a participatory qualitative research tool, if the participants give their informed consent. The drawings and paintings are data in themselves, and can also be supplemented with interviews or writing.

I used body mapping as a research technique to support women to explore and share their experiences through creative means, with the intention that this facilitates greater sharing and offers an alternative to discussion, for those participants who prefer it. The drawings themselves are a form of data, and were also a subject of discussion – providing further data for analysis as women presented and described their drawings and their feelings about them (Richards 2011). Visual methods such as body mapping can aid participation by increasing participant 'ownership' of the process and providing an accessible route in to sharing and discussion (Richards 2011).

The second phase of data collection was **stakeholder interviews**. Stakeholders, including clinicians, researchers, service providers, policy analysts, and older women living with HIV with an additional professional involvement in services, research or policy were recruited based on a stakeholder mapping exercise. Interviews were semi-structured and informed by a review of relevant policy. The findings from these interviews are presented in chapter five.

The next phase of the research was **life story interviews**. Life story is an interview approach that offers a more balanced, power-neutral and wide-ranging interaction between the researcher and participant, and deeper exploration of key issues and meanings. The method has been developed and elucidated by Robert Atkinson, who roots the method in the recognition that people are natural storytellers (Atkinson 2012, no page number):

Our life stories connect us to our roots, give us direction, validate our own experience, and restore value to our lives.

As a method, the life story interview helps us to understand the making of meaning, construction and reconstruction of experiences and understanding of the individual's life. It further brings out the individual voice of the storyteller, built on respect and regard for them and their subjective meanings, with a focus on equitable exchange between the researcher and the storyteller. This supports a balanced relationship, and a degree of mutuality and sensitivity where benefits to the participant are not outweighed by the objectives of the researcher. Atkinson suggests it has particular value in studies with older participants, as it encourages a whole life 'look back' approach.

The interview itself is open, with the researcher asking broad prompt questions, such as (Atkinson 1998):

- What were the most influential events on you in your adult life?
- How would you describe yourself?
- What is different or unique about your community?

The life story method is particularly suited to feminist and participatory research, preserving and prioritising the voice of the individual and privileging their own sense of what is valid, relevant, and important. Life story interviewing builds interconnectedness and lessens the divide between the researcher and

interviewee, and enables a wider and deeper understanding of identity and experiences (Atkinson 2012). Demographics and other details are presented in Chapter six.

The final phase of this research was **participatory data analysis** conducted through a workshop, described in detail in Chapter six. This process engaged older women living with HIV in analysing transcript excerpts, developing and grouping codes and exploring meanings and themes.

4.2.3 Ethics

This study was reviewed and granted ethical approval by the University of Greenwich Research Ethics Committee (see Appendix 6). The formal ethical process considered the research design, methods, recruitment and issues such as informed consent, confidentiality and the collection and safe storage of data. Informed consent was required for all participants in this study. UREC reviewed and approved participant information sheets and informed consent forms. All identifying data was stored in password protected files on the University server and kept separate from research data, which was identified only by participant identification numbers. A mobile phone was used, with UREC approval, to recruit study participants, this was a separate phone and number from my regular phone, and used only during office hours.

In addition to the formal ethical requirements determined by this process, which were adhered to, additional ethical consideration has been taken, in relation to factors such as reflexivity and participation. Specific ethical dimensions of research on ageing and HIV were also considered (von Lob 2012).

4.2.4 Collaboration

This study benefited from collaboration with others, including organisations that supported recruitment, hosted workshops and provided interview space: Food Chain, Naz Project London, AHPN, THT and Body and Soul. In addition to the practical support these third sector organisations have offered, collaborating with them helps to ensure that the findings of my research are shared and put into action. In addition to this thesis, and academic outputs, I worked with partners to produce accessible evidence summaries, policy recommendations and similar tools for dissemination.

I have additionally sought collaboration with other research studies, including meeting with the lead researchers on PRIME and POPPY studies on menopause and ageing respectively, to explore opportunities to collaborate and cross-pollinate our research (POPPY 2015, PRIME 2015).

I have also had personal communications with researchers with similar interests. Patricia Waldron, a clinical nurse manager in a specialist HIV unit in the 1980s and director of nursing at an HIV specialist hospital highlighted the persistence of stigma, the lack of preparedness in elderly care facilities to meet the needs of older people living with HIV and the spiritual and familial dimensions of support needed by people living with HIV (personal communication, phone call, 29th September 2015). Jenny Hislop, who led a study on women's experiences of menopause, shared useful advice on recruiting women and the key themes that emerged in her work (personal communication, phone call, 21st January 2016). Both provided invaluable insight that shaped my research.

In this chapter, I have presented the methodological considerations that underpin this study, and the methods and study design adopted. Based on this, and the empirical and theoretical foundations outlined in previous chapters, I conducted a review of relevant policy and a series of stakeholder interviews, which are presented in the next chapter.

5. POLICY CONTEXT AND STAKEHOLDER INTERVIEWS

In this chapter, I present an overview of policy on ageing and HIV in England, building from and updating a comprehensive review of HIV and ageing policy published in 2014 by the organisation 2020 Health (Beer, James et al. 2014). I focus on ageing broadly, as the lack of focus on gender in HIV-related policy precludes the possibility of a review on gender and HIV, however, gender was explored in the stakeholder interviews presented later in this chapter. The 2020 Health review was undertaken shortly after significant changes were made to the policy and commissioning environment for HIV, so provides a useful starting point. It is also the most comprehensive review undertaken of HIV policy with a focus on ageing to date, and offers a unique, detailed insight into relevant policy and commissioning structures.

I then present the findings from interviews with 'stakeholders' with expertise on women, ageing and HIV. These included clinicians, researchers, third sector professionals and policy staff, and women living with HIV. These interviews focused on policy, and more broadly on the context of services and support for women ageing with HIV, from the perspective of experts, and so further inform the findings of the policy review. I discuss the findings of these interviews with reference to both the policy review and my own research findings. The aim of this chapter is to situate my research within the wider context of HIV and ageing in the UK, and explore key issues identified by stakeholders which influence the future direction of my project, specifically, considerations for the life story interviews to follow.

5.1 Policy context

The 2020 Health report, titled *Growing older positively: The challenge of ageing with HIV* details the results of a review conducted in the second half of 2013 (Beer, James et al. 2014). The review explored the policy context related to ageing with HIV, following the 2013 Health and Social Care Act, which made significant changes to the commissioning and delivery of HIV care and services. It was funded by Gilead, a pharmaceutical company with significant commercial interests in HIV medications, but was conducted independently by 2020 Health,

a social enterprise and think tank. This kind of funding arrangement is very common in HIV research and in my own experience of working on projects of this type, I am assured that sufficient checks and balances are in place to ensure the rigour of the approach. The review included evidence on HIV and ageing policy, care and treatment. In addition, it included 14 in-depth semi-structured telephone interviews with stakeholders and a roundtable discussion. I participated in both processes in my capacity as Acting CEO of the African Health Policy Network. The review was supported by an expert steering group.

The review aimed to explore the implications of new commissioning arrangements on both services and patients, with the latter group split to focus separately on older people diagnosed with HIV in later life, and older people who had lived with HIV from a younger age. It also sought to explore patient choice and new settings for managing care, and to gain insights around treating HIV and co-morbidities.

The methodology adopted for the literature review is not described in the report, so it is unclear what search strategy and inclusion criteria were used. This is a significant limitation in its value. However, the desk review was a first step, which shaped the stakeholder discussion and interviews, where findings were shared and reviewed.

Participants in the interviews, roundtable and expert steering group are listed in the appendix to the report. From the information given, and my own knowledge of some of the individuals named, it does not seem that any person representing people living with HIV was included in the expert steering group. By this I mean that no one is listed as a patient representative, or is a publicly disclosed HIV positive advocate. Among the interviewees, three people are publicly disclosed as living with HIV, though not indicated as such in this document. Similarly, three roundtable participants are advocates living with HIV (two of whom were also interviewed). In each case, there were two men, and one woman, and all are white. The participation or involvement of people living with HIV in the review is not discussed, and seems to have been somewhat limited, particularly in the absence of representation of the diverse population of older people living with

HIV, and lack of involvement in the steering group. Therefore, though the review is useful, it should be considered in the context of that limitation.

Interestingly, the 2020 report draws out a greater distinction than is common in other research between people living long-term with HIV, and people diagnosed with HIV in later life (Beer, James et al. 2014). It identifies specific needs affecting each group, with those over 50 when diagnosed identified as facing problems around GP awareness, support after diagnosis, response to anxieties, and “different needs of men and women” (Beer, James et al. 2014, p.15). Those living long-term with HIV, conversely, are described as most affected by “progression of support into later life; polypharmacy; financial concerns; unknowns of living longer with HIV; changing patient profile re[garding] emotional, social needs; post-traumatic stress” (Beer, James et al. 2014, p.15). Shared challenges are identified as “stigma; mental health; co-morbidities; patient information and education” (Beer, James et al. 2014, p.15). It is immediately striking that different needs of men and women are described as a challenge only for those diagnosed in older age. It is not clear why this should be the case, particularly with biological and social issues such as menopause and care needs that are common to all regardless of time of diagnosis.

The report authors identify six themes which impact on older people living with HIV and shape their experiences: HIV treatment; co-morbidities; mental health; social care; work and finance; and stigma. These reflect the themes that emerged in my literature review on ageing, women and HIV, but with some gaps, specifically: social networks and relationships, loneliness and isolation (though this is partially addressed under mental health), disclosure and ageism. This may well reflect the policy focus of the 2020 review, but it is interesting that these issues did emerge in the stakeholder interviews presented later in this chapter, which perhaps indicates that a narrow policy focus does not reflect the breadth of experiences experts identify as relevant in services and support for older people living with HIV.

The report identifies seven areas of challenges around care and services for older people living with HIV, and recommendations to address these challenges. These include appropriate HIV treatment in older age, which the authors find is

undermined by a lack of leadership and poor communication between primary and secondary care providers, in particular barriers to effective working relationships between GPs and specialists.

Commissioning is the second challenge identified, in particular a narrow focus on HIV and a lack of attention to commissioning effectively to also address co-morbidities. In addition, the new commissioning arrangements implemented under the Health and Social Care Act 2013, which split HIV commissioning between Local Authorities, Clinical Commissioning Groups and Clinical Reference Groups for Specialised Commissioning, are identified as potentially generating confusion, though the authors acknowledge that at the time of developing the report these arrangements were too new to evaluate fully.

Service design is also identified as a challenge, including failure to involve patients, barriers to integrating primary and secondary care and HIV services with those for co-morbidities, and patient concerns around discriminatory or poor treatment. The authors suggest that both the quality of care and identifying the best place or service from which to deliver care should be priorities. Achieving this, they suggest, depends on the voluntary sector generally and peer support services in particular being properly resourced and engaged as experts.

Additional challenges include managing and providing appropriate care for co-morbidities and mental health, and meeting social care needs. Finally, patient involvement is identified as an area where improvement is warranted.

In summary, the 2020 Health review suggests that managing complex needs that cut across HIV and other health conditions, and across health and social care services and commissioning, in the context of reduced funding and new, more complicated funding arrangements, is the overall challenge for HIV and ageing policy in the UK (Beer, James et al. 2014). At the time of their review, the arrangements following the Health and Social Care Act 2013 were very new, and it is likely that in the intervening period, as new systems have bedded in, that some changes may have occurred. This is something I explored in the stakeholder interviews, discussed later in this chapter. Since the publication of the 2020 Health report, other relevant publications have also been added to the evidence base, which I will briefly consider here.

The year after the 2020 Health report was published, the National AIDS Trust published guidance on HIV for social care providers in the UK (NAT 2015a). The guide is designed both for hands-on care workers, and others who manage or commission care, to support them to deliver care that is appropriate for older people living with HIV. It covers basic information about HIV, including testing, treatment and transmission, and promotes the necessity of confidentiality, non-discrimination, using appropriate language and avoiding unnecessary and stigmatising actions over unfounded transmission worries (e.g. the practice of wearing two pairs of gloves). The guide is written for care workers and providers so highlights poor practice without criticism, simply highlighting what is unnecessary rather than describing it as discriminatory. In addition to social and personal care, the guide also includes best practice advice for supporting the medical management of HIV and for psychological support.

NAT also includes a section in the guide on relationships and sexual health, which makes a number of important points around the rights of older people to have sexual relationships, and the role of care providers in supporting this. However, there is an important limitation in the other element to this section of the guidance (NAT 2015a, p.29):

For gay men who may not have children of their own, friends and other HIV positive people may have a more important role to play than traditional family networks. Care providers should ensure that visitors who are not immediate family are made welcome.

Of course, as highlighted in the participatory literature review I reported earlier in this thesis, the same can be true of women (or indeed of anyone) living with HIV. There is no essential correlation between heterosexuality and having children. The role of friends and other people living with HIV can be centrally important in a social network for anyone living with HIV, regardless of gender or sexuality. This demonstrates the value in taking a gendered approach to considering HIV and ageing, as such omissions and assumptions otherwise go unchallenged.

More recently, the All-Party Parliamentary Group (APPG) on HIV and AIDS launched a report on the impact of the Health and Social Care Act on HIV services (APPG on HIV and AIDS 2016). This report conveys the findings of an inquiry into the extent to which changes created by the Act had led to fragmentation in

HIV services. The inquiry concluded that fragmentation has occurred since the implementation of the Act, as predicted by the 2020 Health report. The areas identified as subject to fragmentation, in the evidence received by the inquiry, included HIV support services, described as particularly vulnerable to loss of funding and leadership following the Act. This is because the Act did not make clear where commissioning responsibilities for such services lie, leading to different agencies 'passing the buck'. In the context of a reduced funding envelope overall, services that do not have clear commissioning responsibility are especially vulnerable, and the inquiry highlights a number of services and Local Authorities where such cuts have either been implemented or are planned.

More evidence of these cuts was found by NAT, and published in a review of HIV support services in the UK based on Freedom of Information requests to public bodies with commissioning responsibilities (NAT 2017). In England, NAT identify a trend of reduced investment in HIV support services with a 28% reduction in funding from local authorities between the years 2015-2016 and 2016-2017, based on available data. In London, NAT found a 20.9% decrease in funding for support services, less than the England average of 31% but still significant. Recommendations in the report include the need for all authorities with potential commissioning responsibilities to work collaboratively to ensure adequate services are provided. NAT outline the value of HIV-specific support services as threefold: generic services may be uninformed about HIV so unable to meet the complex needs it entails; stigma is an ongoing challenge and may be a barrier to accessing other services; and, thirdly the specific needs of people ageing with HIV (NAT 2017).

In the US context, a national training and technical assistance body recently published *Strategies to improve the health of older adults living with HIV* (The National Center for Innovation in HIV Care 2016). The report provides recommendations and tools to provide appropriate and supportive care, including specialised training for all staff, screening and testing for co-morbidities including mental health conditions, and strengthening social networks to reduce isolation.

To mark the International Day of Older Persons, on 1st October in 2016, the International Community of Women living with HIV (ICW) released a statement

to their global mailing list, calling for an end to ageism in the HIV response, for more and better research on women's experiences ageing with HIV, and more data disaggregation by age and gender to inform programmes and policy (ICW 2016). This indicates a growing attention to ageing and the needs of older people living with HIV, within advocacy as well as research. The distinct needs of people living with HIV across the life course are also recognised by UNAIDS, which published a report on this subject in 2016, including a section on the needs of people aged over 50 (UNAIDS 2016). In both these publications, the need for better understanding of what it means to age with HIV, including health and social outcomes, is underscored, a growing theme in HIV policy at global and national levels. This increased recognition is important, as indicated by the gaps in policy and provision evident in the UK context.

5.2 Stakeholder interviews

I conducted 10 semi-structured interviews with stakeholders, identified through a mapping of the sector and my own knowledge of relevant actors (topic guide at Appendix 7). The invited interviewees were chosen to reflect a broad cross-section of those with a stake in the topic of ageing, HIV and women, but are not intended to be representative. Each interview lasted about one hour, eight were conducted by Skype and two in person, and all were recorded. I took notes during the calls and used these notes, and the recording, to create a short synopsis of the interview. These synopses were then used for analysis.

The interviewees, designated by professional role, were:

- 1) HIV consultant and policy specialist
- 2) HIV policy specialist
- 3) HIV service provider
- 4) HIV consultant 1
- 5) HIV service provider and advocate
- 6) HIV researcher – academic
- 7) HIV researcher – third sector
- 8) HIV consultant and researcher
- 9) HIV advocate

10) HIV consultant 2

During the interview, I shared a list of the major themes that had so far emerged in the study, so interviewees had an opportunity to respond to emerging findings, after responding to general questions about women, ageing and HIV policy and other issues.

I thematically analysed the responses to each question, and then combined themes across questions to create an overall thematic framework. The themes that emerged from the stakeholder interviews were diverse, and resonated with the themes that have emerged through previous phases of my research, though with some additions. The thematic findings follow in this section, and in the next section I analyse them in the context of the policy review.

5.2.1 Introduction to findings from stakeholder interviews

Participants all agreed ageing is an important issue to address in their work, across the spectrum of research, policy, advocacy and clinical care. This was often attributed to the growing number of older people living with HIV. The challenge of an ageing cohort of patients was particularly identified, with one participant noting how the HIV epidemic had previously predominantly been amongst young people, and there was now a need for significant change as the patient population aged:

That's because we've won a lot of the major battles clinically, we have drugs that work, they are relatively free of side effects. We know how to achieve virological suppression. We've done all of that stuff and we've done it successfully, and patients are now living, they're going to live a normal life expectancy. So we're entering an era where the scope of our clinical work has had to broaden, and it's not really about managing HIV, it's managing everything that comes alongside living with HIV for a long time. (HIV consultant and researcher).

Participants described challenges related to ageing for women living with HIV, including: loneliness and worries for the future, social care and the health system, managing co-morbidities, accessing adequate healthcare, and uncertainty. One participant, a researcher on ageing and HIV, described the process of normalisation of HIV as a particular challenge, leading to a loss of attention and resources for specialised care and support.

Participants highlighted a definitional challenge in 'ageing' and HIV, with one stating this led to issues in research where participants are often in their 50s and looking to their immediate and current experiences, rather than providing insight into the needs of people in their 60s and 70s, where care needs in particular would be very different. This participant, a researcher, suggested there was a "crisis brewing" in social care and a need to look ahead.

Another participant, an HIV consultant, also suggested the 50 plus definition posed a challenge in meeting healthcare needs, as it differs from the definition of 'older patients' used across the health system. This could pose challenges in delivering integrated services. One researcher pointed out that in the findings of her study on ageing and HIV, there were significant differences between respondents aged 50-60, who had lower wellbeing, more challenges with HIV and age-related self-stigma, and more financial problems, compared to the 65 and over participants, who were more likely to have higher self-acceptance and fewer concerns for the future.

Participants who provided services for women described these as being particularly critical for older women. One provided menopause workshops as part of a wider package of services, and suggested that these were well received, and necessary as there were few other support groups providing information in safe, women-only environments. Another described how some women had been accessing the women's support group she runs for almost two decades, and that their continued use of the service highlighted the range of needs outside treatment that women living with HIV have:

There are women who have been coming to our group since I started working here 17 years ago, they are still coming, so then I think like 'wow, that we are failing them', because they are not moving on, doing other things. But then at the same time they are still coming because this is a safe space for them, and, you know, things are good in a way because they are still alive, but then at the same time the support, the social support that we offer is still really important. (HIV service provider and advocate)

She went on to describe how a shift to a medicalised model of HIV, with a focus on treatment, had closed down spaces to talk about wider issues such as quality of life, which nevertheless remained crucial. This was echoed by another

participant who described how HIV affected all areas critical to living a good life, not just health but also financial security, family and self-esteem.

The uncertainty of ageing and HIV was also seen as a reason to pay attention to the issue, as both a research deficit and a source of concern for women themselves.

When presented with the list of emerging themes from my research, all participants felt they resonated with their own experiences or expectations, though to different extents. I shared this list towards the end of the interviews, after participants had responded with their own views to a range of questions. It was a useful exercise in allowing for a 'sense-check' of findings with people with expertise in different areas of HIV, and allowed for topics to be introduced for reflection and feedback.

Given those themes were shared, they naturally re-occurred in the thematic analysis I conducted of the stakeholder interview synopses, alongside other themes.

5.2.2 HIV policy, commissioning and services

The health system dominated many interviews, particularly reflections on the impact of changes to the structure and commissioning of HIV services, outlined earlier in this chapter. These changes were challenging both for clinicians and for people living with HIV adapting to a complex system that could be difficult to navigate, especially for those living long-term with HIV who were used to the previous system. This was further complicated by changing health needs as people age:

There is so much change. You got old, and you got even more complicated health and the services are shrinking and you've got less time. (HIV service provider and advocate)

Both advocates interviewed suggested there were gaps for women as their specific needs were not attended to:

I think that still generally the health services and HIV services are quite gender-blind... you think it would be a given that you need safe spaces for women, women-only spaces but it is not like that. And because resources are scarce at the moment you find yourself competing for a very small pot. (HIV service provider and advocate)

The view that limited funding is restricting the services that can be provided was also evident in the contributions made by HIV consultants. One described it as personally challenging, as she knows her patients would like an integrated women's health service, delivered within HIV clinics, which she would like to provide but is impossible to fund. She also described the challenges consultants are facing as a result of increasing pressure to encourage patients into primary care, when patients themselves have concerns about this. In her description, the current landscape is one of shorter appointment times, restricted ability to prescribe medications or order procedures that were once available, and difficulties potentially arising in the patient-doctor relationship as a result.

Similar views were expressed by other consultants interviewed. One consultant did say that they felt there was no limitation on care due to funding, and that high quality services were available to everyone, suggesting the complaints over, for example, taking two pills instead of one (as a result of cost-saving shifts to using generic drugs) were just "prima donnas" and not legitimate concerns. However, this consultant also described the increasing need to refer to GPs as problematic, based on concerns over stigma and lack of HIV knowledge.

Three participants, two consultants and one policy specialist, indicated that additional research into women's relationship with and views of health services as they age with HIV would be valuable. Suggestions included exploring women's views of changes in services, such as the shift to GPs, and their understanding and feelings about it

Reductions in funding amidst the wider government programme of austerity were described as a problem both in funding health services, such as preventing the establishment of dedicated menopause services, and for social support services. One service provider described funding as "always a problem" and an advocate described how her own support group had been affected by cuts. Social and activity-based services were described by one researcher as needed but often unavailable. Wider changes impacting women living with HIV included assessments for disability benefits and reductions to benefits. In some cases, whole services offering support had been cut, such as specialist support provided by local authorities.

Peer support and support groups were praised by a number of respondents, who felt these were critical for women in particular, and needed to be maintained, in addition to options such as online support. One interviewee suggested that it would be valuable to have more information about what support services are available across the country and how many women are accessing these services.

Problems were also identified in the social care system. Describing her study with older people living with HIV, an academic researcher suggested that few people ageing with HIV had prepared financially or practically for an older age they had not expected to live to see, compounded by the general lack of preparation for older age common across society. As well as individual lack of preparation, she also suggested that the social care system did not understand and was not prepared to meet the needs of people living with HIV.

Interestingly, both this researcher and an HIV consultant suggested that concerns about formal care did not arise frequently, and when they did were more common among gay men, who feared the impact of homophobia. However, other participants suggested women did have these concerns.

While largely subsumed under concerns about social care or health, one participant, an HIV consultant and policy specialist, did make a wider observation about the policy and commissioning landscape, which is instructive in the context of the challenges identified by 2020 Health. She said:

With the policy agenda at the moment and the commissioning arrangements, the way that the needs of older people are met, both medically and socially, and the interface with HIV has never been more complicated, and we're not getting it right at the sort of CCG or Commissioning Board level. (HIV consultant and policy specialist)

She suggested the system made it difficult to build links between services and across distinct commissioning structures, leading to services that are “under-developed” and “under-resourced”.

5.2.3 Specificity of women's experiences

Given that HIV research focused on women is relatively uncommon, many participants reflected on the focus of this study. For some, the specificity of women's experiences invited or even demanded focused attention, and women-specific services or support. The HIV service provider suggested that given the

epidemiological focus on gay men and black Africans, women as a group have not been prioritised, so their specific needs have not been identified or understood:

I think to a certain extent the voice of women has been quiet and been overlooked. (HIV service provider)

This was echoed by the third sector researcher interviewed, who suggested there was a need for women-specific work, as in mixed-gender studies it was easy for men to dominate.

For the HIV policy specialist interviewed, this was a question as much about strategic approach as about inclusion. He suggested that there was, in policy and advocacy, a balance to strike between focusing on the whole, and singling out groups, and that specificity was key to this:

There are some issues that are specific to women living with HIV inherently, and there are other issues where specificity relates to the disproportionate prevalence of a particular need or issue within women living with HIV compared to their peers, as it were, in the wider HIV positive population. (HIV policy specialist)

Given that women within the population of people living with HIV are more likely to be affected by issues such as access to treatment for undocumented migrants, he suggested, the campaigning victory of securing treatment for this group disproportionately benefitted women. He argued that this could be applied across campaign areas, where disproportionate benefit would accrue from having been disproportionately negatively affected. He reflected on how capacity and resources would affect the ability to highlight or drill down into specific needs, concluding that it required further thought, and that more could be done to focus on issues specific to women such as Intimate Partner Violence (IPV):

We do deploy the specific needs of women in a wider argument as well. Is it ever enough simply to make a generic case for some policy change and not go into specificities around particular communities? Well we certainly do that, in other areas, I guess there's an interesting question as to, is that ever ok? (HIV policy specialist)

Another participant, HIV consultant 2, described his view that many of the issues around ageing with HIV were also applicable to men, not specific to women. He suggested that there were broad challenges around taking research findings into practice, but these applied across the board, and that issues often associated

with women, such as childcare and domestic violence, affected gay men as well. At the policy level he argued for the need for guidelines and best practice to be universal, suggesting that:

They [patients] don't want exceptionalism because it smacks of tokenism and it also I think then marginalises the ability to improve things for everybody. (HIV consultant 2)

He further argued that everyone should get the same and equal services, because differential treatment could lead to exceptionalism. However, he also suggested there was a need to create spaces for groups to meet and share issues, and that there may be a difference in how different groups experience shared issues, such as isolation, that would demand tailored approaches. This apparent discrepancy in views was evident across the interview, and perhaps reflected an aim to argue for equal treatment, attention and investment, over a true sense of identical needs.

Much of the discussion around specificity for some participants focused on comparisons with gay men, perhaps inevitable as the group most affected by HIV in the UK. Often this was in the context of more services or support being available for gay men. This view was evident in the observation made by a service provider, that as gay men were most affected from the early days of the epidemic, there was a history of community response and activism, which was only more recently emerging for women. He suggested that this meant that women did not have the same support networks, and were more likely to fear disclosure and the impact this might have, particularly as HIV was still often seen as something that only affected gay men.

5.2.4 Diversity of experiences between people living with HIV

Many interviewees suggested that the diversity of people living with HIV, including diversity among women living with HIV, warranted further attention, especially differences due to ethnicity and sexuality. One researcher suggested her research had demonstrated that older people living with HIV are not a single group, and a range of factors influence their experiences and need for services. Other respondents pointed to sexuality and gender identity as influencing women's experiences of ageing and HIV, suggesting there was insufficient representation and recognition of these diverse identities among women living

with HIV. All researchers interviewed described their own research as not having included, or sufficiently included, trans, lesbian and/or bisexual women, and identified this as a gap in the evidence base.

The specific needs of white heterosexual women were frequently highlighted. The HIV service provider suggested there was an increase in the number of white heterosexual women being diagnosed with HIV, but no corresponding increase in attention to or investment in meeting their needs. In some cases, respondents argued that white women struggled to access safe spaces and support, and felt neglected as a result:

I don't think that they feel that they have got a coherent safe place to meet other people and to talk to each other. I think that they do feel side-lined because they are side-lined. (Researcher - academic)

The third sector researcher suggested this also created differences in the impact of diagnosis, with white women experiencing diagnosis as more shocking and difficult to accept, as they had little information about HIV and had not been targeted by prevention interventions. The academic researcher suggested that the diagnosis experience left white heterosexual women "much more psychologically damaged" than black African women, for whom the experience was much more bound up in culture and migration, and who were more likely to have existing knowledge or experience of HIV pre-diagnosis.

Additional factors identified included faith, with religion offering in some cases positive support, and in other cases barriers to care. An HIV consultant suggested some patients with religious faith were refusing treatment on the advice and encouragement of faith leaders. Geographic location, socio-economic differences and employment were also highlighted, as areas where the needs of women could differ significantly and so tailored support was required.

Within the wider population of people living with HIV, another point of difference for women identified by an advocate was treatment literacy. She suggested that women were less likely to have an understanding of treatment and of developments such as treatment as prevention, so were less likely to benefit from this knowledge. Existing treatment literacy efforts had been, she argued, led by and created for gay men, and were often challenging spaces for women to

access. This was further complicated by the intersectionality of women's experiences, where they were often affected not just by HIV but by poverty, migration and racism.

A number of participants also pointed to diversity in HIV experience itself based on time of diagnosis. The third sector researcher suggested her study had shown those diagnosed pre-treatment were more likely to be affected by co-morbidities, and to be dependent on benefits and have unstable housing. HIV consultant 2 suggested there were in fact three eras of treatment experience, with those diagnosed pre-treatment having undergone significant physical damage due to untreated HIV. Then, those diagnosed after treatment became available in 1996 had access to comparatively poor and toxic treatment, which has had long-term repercussions. He argued there was a cut off in experience, around 2012 or 2013, where very effective and very safe treatments became available, such that those diagnosed since then would have very little damage in the long-term.

5.2.5 Representation and inclusion of women ageing with HIV

The under-representation of women in research related to HIV and/or ageing, and the lack of such research overall, were frequently observed by participants. One researcher who led a study on HIV and ageing described being unable to find any literature on white women and HIV, and the inherent limitations of an evidence base that is predominantly produced either in Africa or with African American women in the US. An HIV consultant and researcher also described the challenges of working with clinical research based on cohort studies that are, she suggested, about 80-90% white men, meaning findings cannot be extrapolated to women effectively.

An advocate living long-term with HIV described the impact of this from the patient perspective, saying that she frequently hears from both her HIV consultant and other specialists that as she is part of the first generation ageing with HIV and antiretrovirals, they have limited ability to answer her questions. She suggested that the experiences of the 'first generation' were generally poor, and she faced a lot of uncertainty in her medical care.

The reasons for this lack of women in research were disputed. One consultant suggested that the research agenda for women and HIV is "lacking in general"

and so ageing is even less represented. Another participant was more critical, saying that the research agenda missed out women as they simply were not prioritised. Other reasons highlighted to explain the gaps in research for women included a tendency to prioritise pregnancy, and neglect women's interests outside or beyond this.

The issue of recruitment of women to research led to perhaps the most diverging set of views that emerged in the stakeholder interviews, which provides an interesting insight. Firstly, the view of an HIV consultant and researcher, with a focus and interest in women specifically:

My feeling, having recruited 800 women into a study reasonably easily, is that women definitely want to be involved in research, you just have to create a study that's meaningful and think about how you're recruiting women and make your study accessible. (HIV consultant and researcher)

She argued that in her own work it had been clear that the barriers were institutional and not about women. If research was designed to appeal to women and be accessible to them, asking questions they found important, and involving women in the research as peers, then in her experience recruitment was not a challenge. She concluded that the real barriers were in fact cultural and institutional, and:

...a real corrosive perception amongst clinicians and academics that women are hard to recruit. (HIV consultant and researcher)

In absolute contrast, HIV consultant 2, who was involved in clinical trial research, argued that it was the case that women were harder to recruit, partly due to women being more worried about changes to treatment.

He described warning research nurses that they would find it difficult to recruit women and this being borne out in his clinic. Responding to the emerging findings from my research on the under-representation of women in HIV and ageing research, he said:

That's their own fault. I have absolutely no sympathy these days because I've spent 30 years trying to get women into clinical trials. If they're not in clinical trials how the hell can we get information? So the fact we have to beg, plead, you know, even for questionnaires. We have a questionnaire here on the menopause called the PRIME study... Do you know what the take-up rate is?

Forty percent. Now I'm sorry, that's, don't come back whinging to me that there's no information. (HIV consultant 2)

Interestingly, the PRIME study is the same research referred to by the other consultant, as the study which has easily recruited 800 women. This would suggest that recruitment is not consistently as challenging as described by HIV consultant 2, and that there are approaches and strategies that can be effective.

The question of women's inclusion and participation did not only arise in relation to research, but also more broadly in respect of advocacy, policy and services. The ideas of 'voices' and 'visibility' reoccurred frequently throughout multiple interviews. In terms of voice, a service provider observed that there is a risk in women not being reached, and therefore a lack of evidence about what women needed from services as they were not heard within them. This was also a barrier to effective advocacy, according to an HIV consultant interviewed, who linked it with disclosure and the broader challenges women faced in being vocal as advocates in the same way as many gay men have been able to.

As well as hearing the voices of women living with HIV, many participants spoke about 'visibility'. HIV consultant 2 suggested there was a need for greater public visibility of older women living with HIV, such as on television. Invisibility was a challenge, one researcher said:

Conceptually I think it is partly to do with the fact that there is just so little out there in terms of our understanding, so I think women quite often aren't as represented in research, they aren't as represented in a lot of just considerations around HIV policy. There was definitely a sense in the women I spoke to, they felt that they were invisible, that nobody consulted them, that people didn't understand living with HIV from their point of view. So there was definitely a sense of them being like the forgotten people or the invisible people. (Researcher – third sector)

This was not only linked to HIV status. An HIV consultant and policy specialist suggested that policy often failed to recognise the needs of older women from ethnic minorities, with this status acting as an "invisibility cloak". A similar point was made by the HIV advocate, who suggested that black African women were frequently not visible, particularly when they were struggling with issues such as access to benefits or the immigration system. It was also associated with sexist and ageist attitudes:

And then there's the much bigger picture about how women living with HIV may need more support, because we're hearing a lot about the stigma of being... Well, first of all, women are meant to be behaving well, and grannies are meant to be good role models for everybody, and grannies who have got sexually transmitted infections are... And so the support for older women is, I think it's lacking because they're not seen, they're more invisible if you like, than almost anybody else. Older women get invisible in general and older women living with HIV are even more invisible. And so I don't think the social support structures are easy and I don't think they're there. (HIV consultant and policy specialist)

Many participants in stakeholder interviews suggested that HIV stigma was affected and perhaps worsened by sexism, and ageism, often in concert. The sense that older women were expected to fulfil a certain social role that was undermined by the presence of HIV was often described, with diverse participants making similar observations to that quoted above.

The academic researcher described how in her study she encountered a particular type of shame associated with HIV amongst those diagnosed later in life, especially for women, which she attributed to having experienced and internalised intersecting ageism and discrimination. She described this linking to fears around disclosure in intimate partnerships, where women feared judgment for not having 'acted their age' or that they 'ought to know better'.

5.2.6 Challenges experienced by women ageing with HIV

Stakeholders identified a range of challenges that older women living with HIV might experience. Socio-economic issues, specifically poverty and reliance on benefits, were associated with both challenges in benefitting from care and barriers to accessing support. For the former, one HIV consultant commented that "the poorer you are the less likely you are to be successful" on HIV treatment and care. Service providers highlighted that immigration processes and poverty could mean that women were unable to access support that was available as they couldn't cover the costs of transport, and so faced greater risks of isolation. Outside this, another observation made by a researcher interviewed was that older women generally face more poverty in older age, having accrued less pension, and that for women also facing ill health and potentially early retirement, this could be an even greater challenge.

Managing complex healthcare needs, especially HIV medication and co-morbidities, were highlighted as significant challenges, along with the burden of navigating complex systems to access care and support.

Specific conditions or needs raised included contraception, osteoporosis, cancers, and menopause. One participant was leading a study on HIV and menopause, and another ran a menopause clinic within an HIV service, so it is unsurprising that menopause featured heavily. It also came up frequently though in other interviews, perhaps reflecting the new attention being paid to the subject as a result of the PRIME study, but also indicating patient interest, as for example in the most recent THT report where menopause emerged as an area where respondents prioritised needing more information (THT 2017).

There was broad agreement that as the first generation to experience menopause with HIV, there was a need for more research, and for greater support from HIV clinicians. There was a sense that progress had been made, with more HIV clinicians speaking to their patients about menopause and more referrals to menopause clinics where available. However, describing her own experience of menopause, one advocate said she had struggled to access information or support from her consultant.

Social isolation was reported as a problem for older people in general, exacerbated by HIV. Two consultants observed that isolation could be different for older women living with HIV compared to older gay men, as they were less likely to be disclosed about their HIV status and to have supportive networks. Disclosure, health problems including as a result of late diagnosis and early toxic treatment, and migration experiences, were all also highlighted as factors that could increase social isolation:

The support they get here is really important because they don't have wide support networks and even if they have, here is the only place they can talk about HIV. (Advocate and service provider)

Disclosure, and specifically the choice or necessity to keep their HIV status secret, was described by a number of interviewees as a barrier for women living with HIV, preventing them from accessing social support from family and friends, limiting their social networks and impacting on their wellbeing.

5.2.7 Relationships and motherhood

A number of interviewees suggested that sex and relationships were under-addressed in research on women, ageing, and HIV and that further research was needed. Some expressed surprise that it was not one of the themes that had emerged in my research so far. Particular challenges for older women with HIV included negotiating condom use after menopause, disclosure to partners, and challenges older women face anyway, outside the context of HIV, in meeting partners and forming relationships. One service provider described how many women attending groups in his service have “almost closed down” the possibility of relationships, and lack information around new developments such as the impact of undetectable viral load on transmission risk, which means they are still held back by concerns around disclosure and transmission.

As well as the emotional benefit of relationships, in terms of support and companionship, participants also stressed that older women living with HIV still expressed desire to have sex and that support for this was often inadequate. For example, one researcher described participants struggling to access lubricants and GPs being unsupportive and unhelpful when these were requested.

Participants also reflected on wider relationships and family connections. Many interviewees discussed motherhood, including the importance of motherhood in women’s lives, and how this shaped their interactions with HIV and worries about the future. The academic researcher described how in her study, almost all women participants were mothers and the role of mother, and sometimes of grandmother, were central to women’s experiences. She described how women diagnosed with HIV in later life worried about the impact this would have on their children, both in terms of disclosure but also worries about future care needs.

Reflections on women who do not have children emerged primarily in response to my sharing that as one of the emerging themes from my study (from the participatory literature review, presented in chapter two). Interestingly, some interviewees suggested that it was something that was overlooked, and had in some cases not been something they themselves had considered.

For women who had been unable to have children as a result of HIV, whether because it formed a barrier to establishing intimate relationships or because of

fears of transmission, menopause could be a particularly challenging, emotional experience, according to the researcher and HIV consultant. She described women experiencing menopause with a “sense of finality” that the opportunity to become a mother had definitively gone, and women feeling emotional and even angry about having lost that opportunity.

Providing care, particularly to parents and children, was seen as a particular challenge for older women living with HIV. One HIV consultant referred to the “double whammy” effect women faced of having to care for others as well as themselves. Care responsibilities could be a barrier to accessing support, according to a service provider. A researcher described how challenges such as memory problems and managing complex treatment and appointments could be an issue for women themselves and in those they provided care for, noting that as well as having to provide care, ageing also involved losing sources of support: “the older you get you end up giving the support rather than getting the support”.

The particular challenges for migrant women, providing support to parents in their country of origin, was noted by one participant, who highlighted the financial, practical and emotional burden this represented as being under-addressed. More broadly, the need to support carers and understand the experiences of women living with HIV within the wider context of their families, networks, and communities, was highlighted as warranting further research and possible intervention.

5.3 Analysis

In this section, I present an analysis of the stakeholder interviews, drawing on the policy summary I presented in section 5.1, and consider:

- whether the same priority issues emerge
- what progress has been made since 2014 on the issues identified
- whether the approach taken in the 2020 Health report, which focuses on three groups most affected by HIV: gay men, African people, and white heterosexuals, is still evident and what effect this has
- if the distinction drawn in the 2020 Health report between the experiences of the long-term diagnosed and those diagnosed in older age is reflected

Drawing on the findings of these stakeholder interviews, it is clear that many of the same issues are evident, including challenges in service design and commissioning arrangements, meeting complex needs and integrating social care and mental health services, and ensuring that there are effective links and communication between different elements of the health system. The 2020 Health report suggested some of the challenges at that time may be linked to the changes having been made very recently. However, it seems that the challenges have not been overcome as the system has become more established. In their review, 2020 Health found that the new commissioning structures could generate confusion, which certainly seems to have been borne out in practice. In particular, the HIV consultants interviewed described services offering less time for patients, who instead were directed to primary care. This is the model that the Health and Social Care Act 2013 intended, so it's clear that the policy has been implemented, but that the impact of this has been at least partly negative.

The focus on an epidemiological model that targets gay men and African people also seems to be intact, but the suggestion that white heterosexuals should also be prioritised for attention is not borne out by stakeholder interviewees, who felt that both men and women in this category had their needs neglected. The 2020 Health report did not identify women as a group, nor consider their needs specifically, reflecting a wider gap evident in other policy documents reviewed. The stakeholder interviews indicate there is a sense of this being a gap in the evidence base, and more recognition of the value in addressing women's needs as a group, though this may reflect the interviewees selected rather than a wider sea change in the field. In fact, some interviewees reflected that they did not generally think about women specifically, but had thought about it only for the purpose of the interview itself.

The distinction drawn in the 2020 Health report between those recently diagnosed, and the long-term diagnosed, was evident in many stakeholder interviews, though the categorisation tended more towards treatment era than length of diagnosis. Interestingly, this tended to conflate availability of treatment with access, such that it was assumed that after 1997 people would have had access to treatment, and when treatment improved they would have had access

to better treatments. This is very likely accurate for people diagnosed and accessing care within the UK, with a publicly funded health system in which treatment advances have been made available as they were developed. But of course many women living with HIV in the UK are originally from elsewhere, particularly African countries where access has been much more challenging.

Among the recommendations made by 2020 Health was a call for investment and resources for third sector support services, especially peer support, as an essential service for older people living with HIV and a vital element of providing quality care. As noted, there has instead been significant disinvestment in these services, at an increasing rate in recent years (APPG on HIV and AIDS 2016, NAT 2017). This view was reflected repeatedly in stakeholder interviews, where participants described funding cuts and growing challenges in securing resources to deliver services, which remained absolutely vital for people living with HIV.

At the time the 2020 Health review was conducted, changes to commissioning were new, and while potential challenges and areas for concern could be identified, it was effectively too soon to judge the impact in practice. The feedback from my stakeholder interviews, conducted four years later, would suggest that the challenges that were predicted have emerged, and that the system, though now embedded in practice, does have a range of difficulties, not least of which is the complicated, fragmented split between commissioning responsibilities across different bodies. Loss of funding has prevented the elements of the system, specifically third sector providers that could have shored up the new approach, from fulfilling that role effectively.

The overarching theme that drew together all the stakeholder interviews was the question of how the complex needs of older women living with HIV could be met effectively when they were not fully understood, in a system trying to do more with less. That remains a huge question to be answered.

5.4 Reflections and influence

This is the first generation to reach old age with HIV, in sufficient numbers to be addressed as a population with specific needs. They are doing so when much

about ageing with HIV, and the long-term impact of HIV treatment, is unknown. And the health system they depend on has undergone significant change, with a push towards primary care and away from the specialist HIV services that many older people living with HIV have trusting and established relationships with. To face so much change, in the context of such uncertainty, is enormously challenging. It is notable that none of the ten stakeholders interviewed expressed support for the new commissioning and health system arrangements. The idea underpinning these changes, that people living with HIV should access primary healthcare in primary care settings, and HIV clinics should focus only on HIV, is not one that participants supported. Instead, they highlighted ongoing challenges with stigma and discrimination in non-specialist settings even within the health service. They described the difficulties people living with HIV faced in navigating complex pathways and referral systems, and treatment and care from multiple providers, in some cases with limited knowledge of HIV.

It may be that these challenges will be overcome with time, but it does mean that there is another arena in which this generation are the 'guinea pigs', and this in itself is a challenge. In the course of conducting the interviews, I was struck by the idea that perhaps it was change itself that was proving to be difficult, rather than the new policy arrangements. In some cases, older women living with HIV have been treated by the same consultant since diagnosis, for decades. They have become used to seeing the clinic as a safe, supportive space, and to having all their healthcare needs addressed there. Changes to this model will perhaps automatically be difficult, and not necessarily reflect problems in the new model.

I put this as a follow-up question in one of the later interviews, to an HIV consultant who had been describing the impact of the new arrangement. I asked if she felt this would be similar for newly diagnosed patients, who had not experienced the previous approach. She reflected that it might be assumed it would only apply to longer-term diagnosed patients, but that she did not think that was the case. In her view, it was a product of the experience of HIV diagnosis, and the very close bond formed between HIV consultants and their patients, who saw them as trusted, safe sources of support and information. The process of diagnosis, facing fears of mortality, adapting to being a patient and living with a long-term condition, and starting treatment, were all difficult and all experienced

with your HIV consultant every step of the way. She concluded this would mean patients diagnosed at any stage of the epidemic and in whatever configuration of the health service would look to their consultant and their clinic as their favoured site for healthcare. In addition, given that HIV remains highly stigmatised, people's experience of both the wider health system and society more generally could involve discriminatory experiences that would lead patients to be more comfortable in the HIV clinic, a non-stigmatising environment by definition.

Of interest, gender-based violence was infrequently mentioned by stakeholders, and in conflicting contexts, with one participant describing it as an issue specifically affecting women that could be given further attention, and another arguing that gay men were as affected by violence as women, so it was wrong to focus on women exclusively. The links between HIV and gender-based violence for women are generally recognised at the global level, and this is a topic I will consider further in the context of the life story interviews.

Trauma linked to diagnosis also featured, but primarily in explicit reference to white heterosexual women. For black African women, diagnosis itself was not really referred to across the interviews, an interesting discrepancy which perhaps reflects that white heterosexual women are more likely to be diagnosed late, but also reflects the view expressed in some interviews that cultural differences around knowledge about HIV, and differential vulnerability to acquiring HIV, affected the impact that diagnosis had on women. This, too, will be explored in the life story interviews.

The issue of specificity was dominant. Whether it was appropriate or constructive to focus on women was a subject that emerged quite differently in different interviews. For many, this was treated as a given, often reflecting the work and focus of those interviewees. For others, especially those whose work did not usually involve a gender lens, it was a question to which they returned in their responses. It is not the aim of this study to offer a comparative analysis of women against gay or heterosexual men ageing with HIV. It is interesting that participants sought nevertheless to provide this, and points to the reality that there is not a focus on women, or on gender, within HIV policy or services, such that to take

this approach is to effectively make an argument for something that is not established or accepted.

One interesting element of this was the sense of the norm that underpinned it. In some cases, treating everyone the same as one population of people living with HIV was advocated for as the proper approach. Yet it was also accepted that there were differences in experiences and in outcomes for individuals. If it is the case that gay men are doing better in terms of access, representation, or care, how then can the case be made for continuing an approach that treats everyone the same, yet produces unequal outcomes? As described previously in this thesis, that approach does dominate, and a gender-based approach is not taken in the HIV response in the UK. In one interview, with a policy specialist, an instrumentalist argument was advanced for this, that there is not sufficient resources or attention to address everything, but that women could still disproportionately benefit from the outcome of initiatives that were not gendered or targeted for women. This was implied too in other interviews where participants referred to improving services for everyone, and women benefitting as a result.

This fundamentally, I suggest, miscasts the role of a gender-based approach, in allowing for issues that are otherwise hidden to emerge. Two groups may share an experience but with entirely different drivers for that experience, such that isolation may seem to be a shared experience but approaches to address it that work for one group will fail for the other. More, the policy approach described above, of 'a rising tide will lift all ships', assumes that inequality between social groups can be overcome by fixing shared problems, yet fails to account for the impact of issues such as gender inequality which are unevenly distributed.

The response to HIV in the UK has been one of crisis response, and this has been used to justify an approach which seeks to meet the basic needs of everyone affected first. Even now, with the loss of funding and changes to the health service, there is an idea, evident in some of these interviews I conducted, that we have to 'get the system right for everyone' first, and then pay attention to specific groups. It is taken that a rough category of 'people living with HIV' will suffice in a time of crisis, and that HIV itself is a sufficiently encompassing category that other elements of experience and identity lose their impact. This

model, though claiming to be about prioritising the whole population, in fact privileges gay men, as the majority within that population. Gay men are constructed as the norm, and what attention should be paid to others becomes a question of addressing 'special interest' groups. The idea of paying specific attention to women becomes one that only follows from issues that only affect women, as suggested by the interviewee who responded to the themes emerging thus far from my research by observing that men are also affected by the issues identified. Perhaps it is also implied by pregnancy coming up in more than one interview, though the focus of the discussion, women aged over 50, are highly unlikely to experience it.

But of course the question 'how are women affected by x?' is not answered by the observation 'men are too'. Whether the two groups are affected in the same way, influenced by the same drivers and causes, and helped by similar responses, can only be assumed if it is first assumed that the two groups are fundamentally the same, barring this one difference of gender, and by further assuming that gender itself does not influence any of those issues. It is fundamental to a feminist approach that neither of these assumptions hold. The HIV response in the UK, as indicated through the stakeholder interviews and more broadly the policy documents reviewed, does seem to rest on these premises.

By adopting a feminist approach, I am making the case that gender impacts the lives and experiences of women living with HIV, and that the experiences of women are under-researched and insufficiently prioritised. In the dominant construction, there is little description and understanding of women as a group affected by HIV. In this study, my aim is in part to do the descriptive work of understanding and defining positively the category of women living with HIV, and to do so not from a comparative model but a foundational approach.

In this chapter, stakeholders shared their insights into the experiences and priorities of women ageing with HIV. In the next chapter, I outline the demographics of women living with HIV who participated in this research, and the methods used to explore their experiences.

6. PARTICIPANT DEMOGRAPHICS, REFLECTIONS AND METHODS IN PRACTICE

In this chapter, I describe participant demographics and data collection from the creative workshops and life story interviews. I then describe how this data was analysed, and close with reflections on the research process, following a typology defined by Dean (2017). The aim of this chapter is to describe what data was collected, from whom, and how. It should be read as a framework to support understanding of the remaining part of this thesis, which presents the main findings from this data.

6.1 Workshops

6.1.1 Workshop recruitment and structure

I held three workshops, each hosted by a third sector organisation that supported recruitment and provided space and refreshments. This support was provided by the Food Chain, NAZ and the African Health Policy Network (AHPN)⁵. Each organisation shared recruitment materials, specifically an invitation and information sheet, directly with their networks.

In the case of the Food Chain and NAZ, women who met the criteria and were interested in participating contacted me directly by phone or email to respond to further questions. I selected participants based on the inclusion criteria (over 50 and living with HIV in London) and to ensure diversity across age, ethnicity and length of diagnosis. Recruitment for the AHPN workshop was carried out directly by AHPN, who confirmed attendance with participants. This allowed for women who did not have access to, or were nervous of using, phone or email, to participate, and so enabled wider participation. The staff member who led the recruitment is well-known and trusted in their network, which also supported recruitment. She recruited based on the inclusion criteria and to secure a diverse mix of ethnicities, length of diagnosis and other experiences. It must be acknowledged that this process may have introduced some bias, however I am

⁵ The Food Chain is a London charity providing nutritional training, shared meals and food deliveries to people living with HIV. NAZ is a service provider focused on people living with HIV from black and minority ethnic communities. AHPN is a policy organisation focused on HIV and African communities.

confident that the steps followed were the same I could have taken independently. I worked with her during my period working for AHPN and so we have a close and effective working relationship that ensured I could be clear on the ideal process and she was able to ask questions to flag any concerns should they have arisen. The workshops at the Food Chain and AHPN were exclusively participants recruited through links with those organisations, whereas the NAZ workshop included both NAZ service users and participants recruited externally, primarily through an advert posted to the UK-CAB forum.

Each workshop was planned to last for about two hours, and although each workshop varied slightly in length, all participants completed the main activities described below. All were recorded, transcribed and anonymised. In addition to the recordings, creative outputs were collected, and notes taken during the workshops. The structure was flexible, including core activities and additional discussion points, used differently depending on group dynamics and flow of discussion. Following an introduction to the research project, information about confidentiality and consent, and the signing of consent forms and provision of expenses, I led the participants in a round of introductions. The workshop then formally opened with a discussion and loose word association activity around both ageing and ageing with HIV. This led into further discussion about individual experiences around ageing.

Approximately 30-45 minutes into the workshop, I introduced the creative activity of body mapping, described in detail below. Participants had been informed that the workshop would include a creative activity, but not specifically what this would involve, so I gave a detailed introduction to body mapping including its origins and applications. As described in chapter four of this thesis, I outlined how I had adapted the technique to use some of the activities in a shorter exercise and that it was a research technique to support women to explore and share their experiences creatively, with the intention that this facilitates greater sharing and offers an alternative to discussion. Participants understood that the maps themselves are part of the research process, and that they would be invited to provide a narrative to describe their maps and the process of creating them.

The body maps were used as a catalyst, to support participants to share their stories and to invite commentary. They were not intended for detailed analysis, and that is not offered within this thesis. Though such analysis would be possible, in this study, the aim of the creative activity was to provide a vehicle for reflection and constructing a narrative, using individual, private reflection before sharing with the group. It further offers a symbol or marker of each participant, to carry her story through the research with a sense of the individual.

The mapping process involved six stages: drawing the body; using symbols and pictures to illustrate where you have come from; using symbols and pictures to describe where you're going; describing your support base; drawing on physical pains and marks; and finally drawing on emotional pains and marks. After moving through the six stages and completing their body maps, I invited each participant in turn to narrate their map, without interruption. The workshop concluded with additional discussion, where I used prompt questions to further explore issues and ideas that had been raised in the body map narratives.

Each group had a different dynamic, but overall I found women were highly engaged and keen to take part. Recruitment was straightforward, suggesting that women do want to participate in research. The creative activity when introduced caused some concern, and some participants expressed a desire not to participate, but with time and reassurance everyone did take part, and indeed the body maps display a high degree of effort and creativity. A number of women expressed disappointment that they were not able to keep their body maps. I did invite participants to get in touch if they wanted copies, however no one did so, suggesting perhaps that the value was attached to the experience itself more than the product.

As the researcher, I found some of the interactions within the workshops quite challenging, particularly some in the Food Chain workshop, where women described very emotionally their experiences of isolation and futility. However, the body mapping opened up quite different narratives, with more space and accounting for hope in many cases.

Each workshop was hosted in the premises of an HIV support organisation, with members of staff on site, who were able to provide support should the need arise.

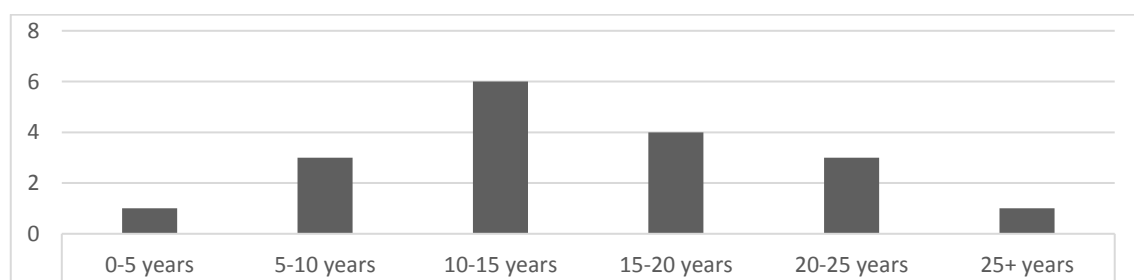
In addition, I provided each participant with a list of support organisations and helplines to contact should they require additional support following the workshop (Appendix 8). During the introduction to the workshops, I informed participants that they were free to leave at any point, including to take some time before re-joining, or to withdraw completely, and that they were also able to choose what questions to answer or discussions to participate in. I ensured all expenses were paid in full before the start of each workshop, to ensure this did not prevent anyone leaving should they want to. In practice, though there were emotional periods in each workshop, there was also a lot of support among the participants, and all ended on positive notes.

In the workshops, stories told in discussion and presented through the body maps were often different in focus, which led me to prioritise engaging with how and why stories are constructed, prioritised and told, in the life story interviews.

6.1.2 Demographics

There were 18 participants in total, in two workshops of 5 people and one (at AHPN) with 8 people. Thirteen women were aged 50-60, four aged 60-70, and one aged 70-80. Fifteen participants described their ethnicity as black African, and three as White British, and correspondingly 15 had migrated to the UK, while three were UK-born. Of the 15 who had migrated to the UK, 12 were born in East and Southern Africa, one in West and Central Africa and two did not answer this question. Fifteen women described themselves as single, one as married and two as widowed. Ten described themselves as having a disability, five no disability (two did not answer, one responded 'sometimes'). I did not collect information on sexuality or gender identity, an oversight corrected in the life story interviews. The time since diagnosis with HIV varied from seven months to 27 years, with most participants having been diagnosed for 10-15 years, as shown in figure 6.1.

Figure 4.1: Length of diagnosis of participants in workshops



6.1.3 Body maps

In the body mapping exercise, conceptualising the future, and fears around it, was a common theme. In general, the body mapping process elicited a narrative construction of having overcome challenges (often linked to HIV diagnosis and/or migration), a sense of coping in the present, and fears for the future. The purpose of the body mapping was to situate the ageing process within the life course and within the body, and to explore both physical and emotional experiences and expectations of the future. Participants took great care over creating their maps, and in sharing their narratives demonstrated that in drawing the map, they had reflected on their experiences and prioritised what to include based on what had most meaning or resonance. The body maps capture both positive and negative experiences, and give a sense of complex lives in which HIV is just one strand.

The narratives that participants shared to describe their body maps were included as verbatim data in the analysis described in section 6.3, and the findings shared in the following chapters of this thesis. A selection of body maps and anonymised narratives from workshop participants are included in Appendix 9.

6.2 Life Story interviews

6.2.1 Life story interviews recruitment and structure

Recruitment for the life story interviews was diversified through different channels and networks. I created a flyer, summarising the research and what participation would involve, with a contact number and email. I also sent a letter to HIV support organisations, requesting their help in recruitment. In addition, I shared recruitment information on Twitter, and the UK-CAB forum. Multiple organisations supported recruitment, in particular Body and Soul, an HIV support organisation in North London, which runs a popular weekly support group. The staff member who organises that group shared recruitment information with older women accessing the service, and in some cases passed on contact details, with consent, for women who were interested but unable to contact me directly.

The screening process was more detailed than for the workshops, as I had identified additional traits that were under-represented and so sought more

information to achieve this diversity. For each individual who expressed interest in participating, I carried out an initial screening over email or phone, to confirm their name, contact email or phone number, and that they met the following participation criteria:

- Living with HIV
- Aged 50 or over
- Identify as a woman
- Live in London and/or linked to services in London

In addition, I outlined the structure of the interview, the possible venues, and confirmed whether they had already participated in a workshop.

Interview venues were provided by HIV support organisations, NAZ, THT and Positively UK, who offered private meeting or counselling rooms that I could book as needed. All but two interviews were conducted in those venues, with one taking place over Skype, and one in the office of the organisation where the participant worked.

After the initial contact, I shared the participant information sheet, and asked the potential participant to read and confirm they were happy to proceed. If so, I assigned the participant a unique identifier, and created a record using this in a separate database for demographic details.

I then held a screening call, including a series of questions, confirming the eligibility criteria above and also the participant's: age, ethnicity, length of diagnosis, migration experience, sexuality, relationship status, employment status and whether they had children. Although a lot of questions to cover in a phone call, I explained that it was to help ensure diverse recruitment, and everyone screened consented to answering in full.

After screening, I determined based on diversity of the sample whether to invite the participant to interview. Interviews were arranged by phone, text or email, depending on the preference expressed at screening. All interviews were held during office hours, on a day and time of the participant's choosing.

Interviews were conducted using a set of prompt questions (included at Appendix 10) either taken or adapted from a guide to life story interviewing (Atkinson 1998).

Each interview lasted a maximum of two hours. I opened each interview by sharing the participant information sheet, and giving expenses (£20 for time and £20 for travel) in cash, for which a receipt was signed. I explained that the participant could withdraw at any time, that the interview would be recorded and transcribed, and that the data would be anonymised, analysed, and used in both the production of my PhD thesis and other publications. With permission, I used two recording devices, and started each interview by explaining the life story interview, and how it differs from other interviews, then asking 'where would you like to start?' Participants differed in their approach to the interview. To give the extreme examples, one participant required only that prompt, and spoke until time ran out, while another, more apprehensive participant, needed all the prompt questions listed at Appendix 10. Each interview varied greatly, depending on the participant, and the dynamic that emerged. Consequently, each narrative is as individual as the woman telling it.

6.2.2 Demographics

In total, fourteen interviews were completed. A 15th was planned but cancelled last minute as the participant was in hospital, unfortunately this was someone aged over 60, which affected the overall diversity of the sample. Of the 14 conducted, participant demographics included:

- 5 White British, 1 White Other, 1 Black British, 7 Black African.
- 9 were migrants to the UK.
- 12 aged 50-60, 2 aged 60-70.
- 2 bisexual women, 1 trans woman.
- 1 diagnosed less than 5 years, 3 for 5-10 years, and 10 for over 10 years.
- 5 currently in relationships.
- 5 currently working.
- 9 had children, 5 did not.

Three of the participants had previously taken part in the workshop phase of this research study. They were invited to participate again due to particular demographic features which helped to create greater diversity in the life story participant sample. Other workshop participants who expressed interest were not

included in the final sample, as I prioritised 'new' participants where diversity would not be enhanced by their inclusion.

In addition to the 14 participants who took part in an interview, 21 other women expressed some interest in participating. Nine of these were contacts shared with me by Body and Soul, of whom four did not respond to my outreach.

Of the remaining 17 who expressed interest but did not participate:

- Two were confirmed but unable to complete an interview due to illness.
- One was confirmed as too young to be eligible after screening.
- One lived outside the target area.
- Four had participated in a workshop, and were not selected again.
- Two contacted after the interview places were full, apart from those with under-represented characteristics (over 60 or recently diagnosed).
- Six decided not to participate or did not respond to follow up.
- One had no contact details available and did not make contact.

The sample is small, so is not representative, though this cannot be the aim with a qualitative study. It was constructed to reflect the diversity of the population of older women living with HIV. Strengths of the sample include a range of lengths of diagnosis, ethnicities and migration experiences and the inclusion of bisexual and trans women. Weaknesses include under-representation of recently diagnosed women and women aged over 60, and no lesbian women.

6.3 Analysis process and methods

6.3.1 Analysis process

All workshops and life story interviews were transcribed in full, anonymised and taken forward for analysis. Participants in life story interviews were given the opportunity to review their own transcript, to confirm accuracy, add any missing details, and to choose their pseudonym. Nine participants requested to review their transcripts. The majority of these sent minor corrections. One participant initially requested significant cuts to her transcript, as she was worried about anonymity, but was satisfied with further anonymising to change or redact details. Where participants did not choose their own pseudonym to use, I used a random

name generator with year of birth and country of origin criteria, and selected an appropriate name from the generated list of options.

The analysis process I used drew on a range of sources and approaches, including guidance from supervisors and a NatCen training I attended on qualitative analysis, as well as relevant literature.

In keeping with good ethical practice, anonymization was the first step, implemented during transcribing: no names were ever included in any transcript, and transcripts were checked for additional potentially identifying details to anonymise (Creswell and Poth 2017). I then followed the three main steps of analysis identified by Creswell and Poth (2017) as organising the data, coding and condensing codes to generate themes, and representing the data, noting that these steps are not fixed or linear. An iterative process of open coding, followed by defining codes and developing descriptions for them, then applying to the data, was adopted (Creswell and Poth 2017).

The process I followed was:

- 1) Open coding of one life story interview transcript, marking up topics being discussed. I then created a table of topics, each with a short sentence description. I then reviewed further transcripts, updating the table to add or combine topics and further refine the explanation.
- 2) I then developed themes and categories, classifying topics based on overlapping or interlinking experiences or definitions. I created an analytical framework as a tree diagram to represent this. The analytical framework and table of topics and definitions are included at Appendix 11, as revised after the participatory analysis workshop described in the next step. The framework is intensely detailed, and the table that follows it includes an exhaustive list of topics and sub-themes. In this stage of the process, I sought to generate a comprehensive overview of what the data told me. In later steps of interpretation, this was whittled down to focus on areas of most interest or impact, and to group together topics with similar meaning. Four main themes and seven sub-categories were developed to encompass the data and define the key findings that are presented here.

- 3) The third stage was a participatory analysis workshop, in which four women living with HIV aged over 50 reviewed transcripts and participated in coding and generation of topics and themes, and reviewed the draft analytical framework. This workshop is described in section 6.3.2.
- 4) I then revised the analytical framework based on the findings of the participatory analysis workshop.
- 5) Finally, I used NVivo 11 software to code all workshop and life story interview transcripts, coding themes as nodes and categories as sub-nodes, and further refining these as needed. During this process, I reviewed data coded to sub-nodes and generated topics to further refine and sort the data, as the original process of open coding generated too many topics to usefully code with.

The quantity of data produced through three workshops and 14 interviews, and the breadth of topics and experiences covered, especially due to the life story technique, outstripped the capacity of one thesis to meaningfully report. The findings presented here are the product of interpretation at each stage of analysis, and represent the themes that resonated most strongly as relevant, particular to this group of participants, and important to share. This prioritisation reflects both participatory analysis and my own interpretation.

In analysing life story data, it is important to remember that the teller of the story is the expert in the experiences they describe, and that meaning is created through the telling of the story and in the interpretation of it, and matters to both the researcher and the participant, with both experiences of interpretation being personal and subjective (Atkinson 1998). Connections within the text and to other life stories, the personal responses that the text evokes and the meaning that is explicit are all relevant to include in analysis.

My interpretation also treats the life stories as narratives of experience not of events, so as to include all elements of the narrative and gives space to address significant events and also reflect on the present and look to the future (Squire 2008). Squire (2008) describes this as “experience-centred narrative research”, which assumes that narratives “are sequential and meaningful; are definitively

human; 're-present' experience, reconstituting it, as well as expressing it; display transformation or change." (Squire, 2008, p.42). Broadly, this means that narratives describe events, but draw also on experiences and thoughts of the present and future, and that the process of constructing and telling stories is necessarily social and part of what makes us human. By "re-present' experiences", Squire is describing how the narrative is constructed and reconstructed, and will never be exactly the same in another telling of it. The interaction between story-teller and listener, and the moment in time, are all influencing how the story is told. This approach reflects my own experiences where some participants involved me in their story – both their perceptions of my priorities or influence as a researcher, and my personal self as a younger woman who might have similar experiences, now or in the future. Finally, Squire (2008) observes that narratives represent personal changes and responses, rather than a narrative arc of event and resolution. The story is not linear or neatly resolved, but looping and ongoing.

The necessary subjectivity of interpretation of findings, and the choice of what to prioritise and present, led me to adopt a participatory analysis process, which provided a space to reflect on how different people with different experiences respond to the same text, and an approach to analysis and generation of topics and themes that ensured the lived experience of HIV and older age was included.

6.3.2 Participatory analysis workshop

The workshop took place on 9th January 2018, from 6pm to 9pm, in the offices of Positively UK in London. Six potential participants were identified and invited to take part. All were women living with HIV, aged over 50, and with experience and expertise in supporting, working with or representing women living with HIV. Four participants were able to take part (and consented to being identified): Angelina Namiba, advocate and facilitator and trainer for women living with HIV; Memory Sachikonye, coordinator of UK-CAB and co-chair of Sophia Forum; Silvia Petretti, deputy CEO of Positively UK and advocate; and, Jane Shepherd, advocate and UK-CAB committee member. Two participants had taken part in earlier phases of the research, Silvia in a stakeholder interview and Jane in the participatory literature review.

In advance of the workshop, I shared by email an eight-page document that contained: an introduction to the research; summary of the research design; purpose of the workshop; research questions; life story interview participant demographics; and data samples for analysis. The latter was made up of excerpts from six life story interviews, selected for diversity in participant demographics, and to reflect different aspects or topics that came up. I chose samples from different parts of the interviews, and tried to do so without referring to the analysis framework, to try to keep it open.

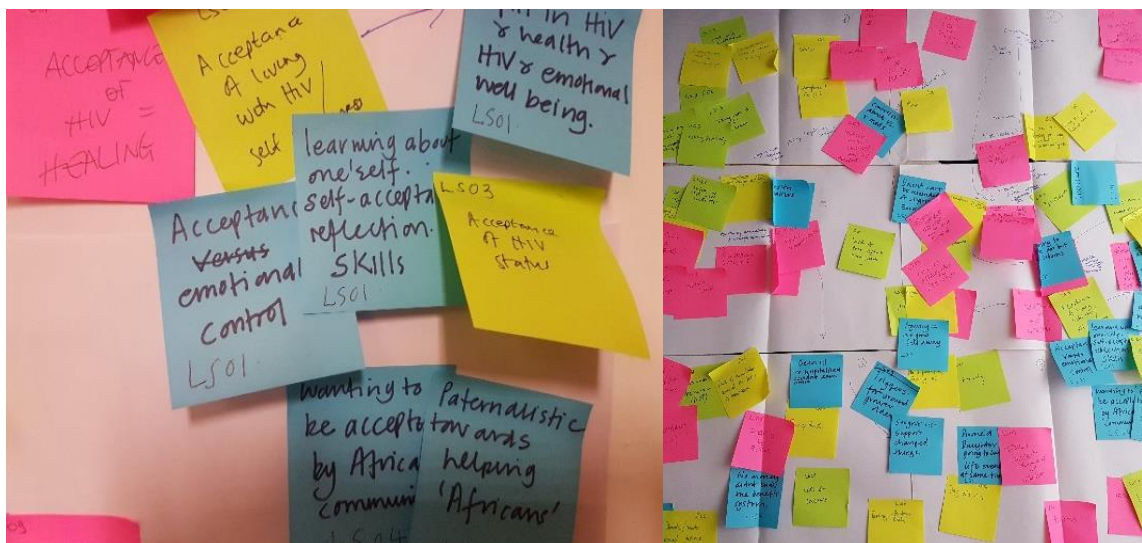
Participants were asked to read the document in advance if possible, but had time within the workshop to review it. I developed an agenda, based on a participatory analysis process described by a social sector impact organisation and adapted to this project (Learning for Action 2017). Broadly, the agenda involved individual review of transcripts and open coding, sharing three codes per participant and creating groups, adding remaining codes and developing or expanding groups, reviewing remaining transcripts separately and adding any new codes that emerged, then a broad discussion of any gaps. Finally, I shared my draft analytical framework with participants for discussion, in particular for any gaps based on their own analysis. Codes were written on individual post-its, marked with the transcript number, and put up on flipchart, which I photographed and retained.

All four participants are women I know, and have worked with in different capacities. This reflects the relatively small number of women living with HIV working specifically on women's issues and experiences: after doing this work for a number of years I know almost all the women involved. The women taking part also all know each other well. This helped in quickly establishing a friendly, warm dynamic in which all participants felt comfortable. The workshop started easily and all participants were focussed and brought attention and preparation to the analysis process.

Listening to the recording to write up the discussion, I can hear that I was at ease, and spoke about the research in some detail in response to questions. It was really useful for me to be able to explain different aspects of the research or answer questions about the transcripts in this environment, as PhD research can

be very solitary, and you lack the opportunity often to 'sense check' your thinking, whereas this allowed me to explore issues that I had struggled over and hear other points of view. The analysis worked very well, with everyone clear on the task and focussed, and it was illuminating to see how differently people can read the same text and the different understandings that might emerge. The discussion was thorough, and brought in both personal experiences and knowledge of the experiences of others, which helped to bring breadth to a study with a necessarily small sample size.

As a researcher and facilitator, it was instructive to be in, as one participant described it "a room full of facilitators". Everyone in the room is used to being the one holding the pen, and this emerged in participants sometimes being very directive in what should be written, or when it was time to move on or re-focus on the topic. This demonstrated a strong sense of commitment to and collective ownership or responsibility for the research broadly, and the stories specifically. Each woman's story was considered in detail, respectfully and in reference to personal experiences.



During the workshop, post-its were put up on a poster made of six sheets of A3 paper, and then grouped together. The result, shown in the photos above, was a sort of spider diagram, of mostly separate groupings, with some connections. The table on the following page shows the grouping title where one was determined, or is clear from the content, and the text from the post-it notes – including x and a number where the same text appeared on multiple post-its. The table is much less visual than the original poster, but captures the content and layout. The

discussion was wide-ranging, and participants shared their own experiences to illuminate their contributions, often discussing similarities or differences with the transcripts under review.

Table 6.1: Themes from participatory analysis

<p>Relationships: Feeling too old for relationships Becoming possible when children leave home</p>	<p>Coping with HIV – social: Layers of stigma: Isolation x2 Loss Acceptance and conflict Shame of being lonely Confusion about symptoms/ageing/menopause Loss of social status Confusion about viral load and meds</p>	<p>Talking about HIV: Continuum – public advocacy to not talking at all Secrecy around talking about HIV Coping with HIV – accepting necessary lies around not breastfeeding etc. Burden of living with a secret Differences between public and private: exposure, vulnerability Talking about HIV x2 Disclosure x2</p>
<p>Wellbeing: Living positively Good quality of life Taking care of oneself – good health Feeling healthier with age</p>	<p>Stigma (links to talking about HIV): Doesn't want to be reminded of stigma, exposure Stigma effect on PLWH – divisive Self-confidence x2 Lack of peer support from friends Lack of appropriate peer age group Agency = stigma fell away Stigma x3</p>	<p>Survivor complex/conflict: Unexpected old age – what now? Survival guilt</p>
<p>Coping with HIV – health: Ability to cope well with HIV Meds and side effects x3 Long-term side effects Energy levels Fluctuating symptoms Burden of uncertainty and always questioning Health matters Lack of control over health Pain management Co-morbidities</p>	<p>HIV as long-term condition (links to acceptance): Long-term diagnosis Living with HIV Not one-off, inconsistent Wanting to move on but HIV returns her Moving on/away from HIV Uncertainty about effects of age, menopause Questions about interplay of HIV, ageing, menopause (not knowing) Split in HIV and health, HIV and emotional wellbeing</p>	<p>Acceptance (links to HIV as long-term condition): Acceptance of HIV = healing Acceptance of living with HIV/self-awareness Acceptance, emotional control Learning about oneself, self-acceptance, reflection skills Acceptance of HIV status</p>

Drawing on the participatory analysis, I reviewed and updated the draft analytical framework I had developed, making changes to themes, categories and topics to reflect the different views expressed in the workshop. The changes were

meaningful, though some of the framework was not changed, there are important differences between the first and revised drafts (the revised draft is included as Appendix 11). I regularly returned to the discussion notes from the analysis workshop as I carried out the coding on NVivo, ensuring that priorities and interpretations were carried through the analysis process.

6.4 Reflections

A workshop or interview is a conversation, an exchange between participant(s) and researcher. Each is individual, even where the template is the same, the interaction is always unique. In carrying out this research, my role and position as researcher was as much part of the process as the participants, perhaps especially in the intense, individual connection of the life story interviews. Where and when the interview was held and the confidence or willingness of the participant, all had an influence. Some women were determined to tell their story, with an explicit aim in sharing, others had never done anything similar before, and were more reticent. Some participants also took part in workshops, or I knew through other channels, which also shaped the dynamic between us as the story was told. In each interview, I made notes about my immediate thoughts and reflections on these issues, and this informed my analysis of the data.

In both collecting and analysing this data, I have worked to adopt a reflexive approach. In his practical guide to reflexivity, Dean (2017) offers a broad, deliberately simplified schema for the complex factors that interlink to produce research practice: “(Personal biography/ position X Research skills/resources) + Site = Research practice” (Dean 2017, p.30). This captures the observation that what is done in the process of research is a product of both who the researcher is, and what they have access to. This is a deceptively simple observation, as it captures some elements which are not always reported in the writing up of a research project. There are elements in this thesis that are the way they are because of factors such as (lack of) funding, my personality and preferences as a researcher, the theoretical positioning of my supervisors influencing what direction I was recommended to go in, and other prosaic issues. Dean’s framework offers an approach to defining these factors so that the reader might

have a fuller picture from which to understand and interpret the findings presented and conclusions drawn. I have presented throughout this thesis reflections on my role as an advocate and as a researcher, and my position in the HIV community. Here, I want to focus on the more practical elements of research practice, following a typology defined by Dean (2017) as: theoretical, methodological, disciplinary, personal, and practical. Collectively, these represent the vectors that encompass research in practice.

Methodological reflections are implicit in the preceding sections of this chapter. The methods chosen reflect my own preferences as a researcher – for example, body mapping is a technique I was previously aware of and was keen to explore. I adapted it to a short activity within a two-hour workshop, rather than a multi-day specialist workshop requiring greater resources and materials. This reflected the resources available for this study, and in other circumstances a different approach could have been taken.

The theoretical framework adopted in this study emerged through discussion and recommendations from my supervisory team and wider readings. My background is in human rights and advocacy, so my pre-existing sociological and theoretical knowledge was limited. The theoretical approach adopted therefore responds to this PhD and not an existing expertise.

My reflections on disciplinary approach are very similar, and quite simple: I do not feel a particular affinity with or belonging to any discipline at such. My research background prior to the PhD was applied research in the third sector. I have studied for my PhD within a Faculty of Education and Health, and had the support of supervisors from different disciplines, as well as the opportunity to present my research to different disciplinary audiences, including medical humanities, sociology, gerontology and applied HIV research. I have learned from each, and present this thesis as a practical, applied and critical health study. I take a range of political, social and methodological tropes and approaches and apply them to the experience of health, with a theoretical inclination but an approach that is empirical and data-driven rather than straight sociology. Dean (2017) describes how disciplinary belonging or identity can narrow the approach, through adopting common practices and the influence of accepted or prevailing

literature or approaches. This is not the case for me, though the converse may be true, and it is possible that a more certain disciplinary home could have produced a different study or analysis.

The practical constraints on any research are similar: the amount of time, money and other resources available all impact what is done, and how it is done. I was funded for three years, and, like many PhD students, worked hard to design and implement a three year study that in reality took over four years to complete. As noted above, the methods adopted were influenced by the limits on additional funding and resources available. The need to finish influenced a thousand small decisions, best summarised as knowing when is enough, though there are ideas or avenues of interest still to explore.

Finally, Dean (2017) suggests personal reflection, covering both personal characteristics and the researcher's position in their field. Reflecting on the interviews and workshops, I think that my age was particularly relevant. I turned 30 just after the workshops, and before starting the interviews. Being at least 20 years younger than the women who participated was often made explicitly relevant by their referring to it, sometimes with observations like 'you're too young to have experienced this yet', and sometimes in the framing of learning as wisdom to be passed on. It affected the personal connection and interaction too. Indeed, perhaps the most rewarding, enriching part of this entire research process for me has been the opportunity to connect with and learn from older women and the lives they have led. I think a researcher the same age as the participants would have heard different tellings of these stories.

That I am not living with HIV was not made explicitly relevant by women taking part in the research. Many participants would have known this, and some also asked, but it was not raised in the way I have experienced it to be during advocacy or other work I have done. This perhaps suggests that the researcher role is defined differently, with different expectations, to that of an advocate.

My position in the field of research did impact on research practice. Being known within the HIV sector and having networks and connections helped recruitment, as organisations and individuals provided support to disseminate recruitment information and to share contacts. It also meant that in both stakeholder and life

story interviews, I interviewed people I knew, and would see again in other contexts, which is likely to have influenced what participants shared. In the life story interviews, two participants were women I already knew reasonably well, and went on to know very well, as we connected through different channels. Others were women I knew of or had some connection with. It is difficult to parse exactly what impact this had. Looking at the transcripts, there is honesty in talking about challenging issues like loss and violence, in interviews with women I knew and was likely to see again. Interviews with participants I had never met, and who are not 'active' in the sector so we are unlikely to cross paths, were sometimes less personal and revealing. Perhaps the existing personal connection made it easier to be open, in participants who chose to sign up for a study with a researcher they knew. For others, I'm sure it could lead to more hesitation in sharing more challenging issues. It is not possible to know what was not shared in an interview, or to know what might have been said to a different researcher in a different context. What I can do is offer an insight to each interviewee and my knowledge of or connection with them, as I introduce their life stories into the text, to enable the reader to draw their own conclusions.

7. MAIN FINDINGS: “I’M STILL HERE”: PERSISTENCE, LIVING AND AGEING WITH HIV AND ‘SURVIVOR CONFLICT’

In this and the following two chapters, I will present the main findings from the life story interviews and participatory creative workshops, drawing also on the participatory analysis workshop. Three themes shape my presentation of these findings: persistence (chapter seven); participation and personal connections (chapter eight); and resilience (chapter nine). In this chapter, I present findings relating to persistence, a term used to encapsulate the experience of living and ageing with HIV and dealing with and moving through challenging experiences.

Each chapter opens with an introduction, followed by findings, structured by sub-theme, in which I present excerpts from women’s stories to illustrate the themes and topics generated in analysis. I present these first in order to give priority to the voices and stories of the women who took part.

The third part of each chapter is a short discussion, in which I bring together the theme and the different strands of it presented in the findings, alongside my own reflections. Finally, the analysis section relates my findings to my research questions, and the earlier parts of this study, especially the conceptual literature review, policy review and stakeholder interviews.

This is an unconventional approach to presenting qualitative data, and it is recognised that it may be more challenging for the reader. However, starting with women’s stories, and then presenting discussion and analysis, privileges those stories and storytellers. Additionally, this structure fulfils a priority identified in the participatory analysis workshop, to avoid presenting data in a way that supports a narrative arc of overcoming or conquering, which a life story approach can unwittingly support. By selecting and presenting data by topic, my aim is to explore the diversity of women’s experiences over time, without assuming or creating an impression of necessary improvement over time.

7.1 Introduction

Six women, in telling their life stories, said, “I’m still here”, a complicated statement that resonates through many of the interview narratives. Something to

celebrate, but also something to make peace with. Negotiating an unexpected older age brings unanticipated challenges, including new health conditions, the loss of parents and friends, and other difficult life events. The uncertainty of ageing with HIV is experienced as a daily burden. HIV is not really survived, it is lived with, every day. In this context, treatment takes on a range of meanings, from something within individual control in lives otherwise subject to ungovernable forces such as the UK immigration system, to a reminder of all those that did not live long enough to access it, to a simple part of a daily routine.

Surviving a terminal diagnosis is an emotional and psychological challenge that for many women is complicated by feelings of gratitude, loss, and fear for the future. Surviving is just the beginning. Living, for decades, with HIV is negotiated with each new milestone reached, and the internal and external meaning of HIV changes with time and age. Beyond this is the prospect of ordinary, mundane mortality, and the challenge of reconciling to normal types of dying. The experience of diagnosis and of HIV-related stigma and discrimination are traumatic or difficult life events for many women, but so too is the loss of loved ones, and experiences of violence, which also shape women's stories. The typical support group narrative of overcoming, of learning and growing, from an HIV diagnosis is problematised by narratives that speak to carrying on, not overcoming. Persisting. In the US Senate, words uttered by a man to describe why a woman was sanctioned for refusing to keep quiet, became a popular rallying cry for the feminist movement: "nevertheless, she persisted" (Wang 2017). This phrase resonated for me as I read and re-read these women's stories. Despite it all, they persisted, and they are still here.

Patricia: Yes I'm taking my medication sometimes, I'm really in pain most of the times, I'm in pain, but however, I'm still here... And I'm like 'I told you, I'm still here, I'm the one who can live with it... So I have done that and I feel really, I feel proud, I feel happy, I feel I've been given a chance. Yeah. I was not meant to be here, and I'm still here.

Yvette: So that's why I'm still here today, because HIV came and then I said, it's not going to kill me. Not today, not tomorrow.

Adanna: Maybe most, most of them [her peers] are now big, big people in a high, high level, I'm still here patching, patching myself like this. I don't like it. I want to go further.

Sara: But that is nothing to do with HIV, that is, I don't know, life, life's changed all of a sudden. Younger people seem to be dying more. And, but it's horrible because it just reminds me of the past, sort of thing. And you, it reminds you that you're still here, and they're not. Why am I, why should I still be here, and they're, and they aren't?

Violeta: And so yeah, so I'm still here, you know. So I'm very proud of that.

Patsy: And I'm still here, 25 odd years after they told me that I'd be dead in six months.

7.2 Themes and findings

7.2.1 'Survivor conflict' – what does it mean to survive?

The concept of 'survivor's guilt' is one I was interested in as I set out on this study, as I had come across it being used to describe experiences of those who had survived the pre-treatment era of the HIV epidemic, and particularly those who had lost friends and partners to AIDS. The term has its roots in the work of Primo Levi, who wrote about his experiences in Nazi concentration camps and reflected on the impact longer-term on those who survived. In his work *The Drowned and the Saved*, he describes the "shame" that survivors experienced, making the case that liberation was not a moment of redemption or joy, but instead of anguish: "the problems of a life to begin all over again amid the rubble, often alone" (Levi 1988, p.73). After the camps, people were forced to confront their experiences, and felt "diminished" by them, Levi argues, as well as by the things they had done in order to survive. From an external viewpoint after the experience, he described himself and others judging their behaviour at that time, and from this deriving feelings of shame or guilt (Levi 1988, p.80):

What guilt? When all was over, the awareness emerged that we had not done anything, or not enough, against the system into which we had been absorbed.

The idea of having survived in the place of another, who may have been somehow more deserving, is described by Levi as rationally dispelled but still plaguing survivors with doubt, a suspicion that "gnaw and rasps" (Levi 1988, p.80). This fear is compounded by his sense that those who survived were more likely those who had behaved with selfishness or even violence or complicity.

Though he does not count himself in those ranks, he feels compelled to question how he survived.

Within Levi's account of guilt there are multiple strands built on reflecting on what aspects of his own behaviour or actions may have helped him to survive, and what moral price these might exact. He also describes the cost of surviving. Starting again, and building from ruins, re-joining life and all its old problems but with a new burden of the memory of suffering, of evil. It is not my intention to draw parallels between the content of the experiences Levi describes and those described by participants in this project. But there are resonances in the emotional process of surviving where others did not, and in life beginning again. Women in their life stories reflected on the achievement and the burden of still being here. Of life and all its attendant challenges, sorrows and losses, re-starting when a premature end was forecast, expected and prepared for.

In the participatory analysis workshop, the women taking part reviewed the transcripts of interviews and recognised in the stories of other women their own experiences of surviving. In discussion, we debated the concept of 'survivor's guilt' because I had not found it in the interviews in the way I might have expected. Below is an edited extract from the discussion that followed. Participants wanted to avoid the language of 'guilt' which did not resonate, but to capture the different emotions involved in surviving, which was evident in the data:

"Maybe we need something new to define this experience of loss of self, loss of future, loss of identity, loss of..."

"I survived something that I wasn't supposed to and I did, I don't have a problem with the term survivor, but I don't identify with the word guilt, I don't feel guilt."

"... coin that one, survivor conflict"

"I think that's a more, much better descriptive term than the guilt one, because you're right, you do go between..."

"You go between positive and negative feelings, a sense of confusion, a sense of, it's very difficult to make sense of it, or to have a rational, logical, completely like, being very happy about it. I am grateful, on a good day."

This concept of 'survivor conflict' is evident in the narratives told by women who have lived long-term with HIV. The process of receiving a terminal diagnosis and

going on to survive, and adapting to a life with HIV and to an unexpected old age, brought a range of complex emotions and challenges into women's lives.

Patsy is a 52-year-old trans women, diagnosed for 24 years. I know her well through work we have done together. She described her sense that surviving a terminal diagnosis must be some kind of achievement, but the challenges she felt in reconciling that to feelings of loss:

... I feel like up to this point, I feel like the challenges, the, the things I've sought out, have kind of worked to a level that feels quite fulfilling most days. And if I take out of the equation, if I try and separate out feeling quite alone, in terms of intimate partners, or an intimate other half or partner, then, then yeah, I mean if, you know, I've kind of achieved quite a lot of what I, I never imagined I'd ever achieve really, so. And I'm still here, 25 odd years after they told me that I'd be dead in six months. I mean that's got to be an achievement.

Rebecca, now 64 and diagnosed 30 years ago, had recently had an aggressive cancer which required serious and debilitating treatment. She described both HIV and cancer as random, yet struggled as a spiritual person to understand the meaning of a second serious illness:

And I think, I think I got tired of being strong as well. Because, I never moaned, never, ever said why me about the HIV and never said why me about the cancer, in fact when someone said 'oh, you know, you'd think you've gone through enough', I said 'well no, at least I've lived long enough to get something I'd naturally get', you know, why not me? I mean, I don't get why people say 'why me?' Why not, you know, it's random... And it was very strange because when I watch something now on TV, that, you know, how cancer's changed people's lives if they've survived, and it's like, it wasn't like that for me. Because I've done all that, do you know what I mean? It wasn't like, oh it's really opened my eyes, about life, because I've been through that one, sort of, and yeah, I couldn't see what it really had to teach me.

Many long-term diagnosed women I interviewed, including Rebecca, talked about the current impact of the un-grieved, unacknowledged loss of the early days. They described a time when there was so much death, and fear of their own deaths, that there was no time or energy to feel or process grief. Survival came with the cost of facing this loss.

Sara, a 55-year-old women diagnosed for 28 years who had also participated in a workshop, also talked about this legacy of loss, with no one left with shared memories, though she also joked about the positive side of this.

Everybody was dead. And that's, I did find that quite hard. And it, it sounds daft, it was silly things like 'oh do you remember when we went to the seaside and x, y, z, happened?' And there's nobody I could ask that was there that would, you know, fill in the blanks that I couldn't remember. So it was quite horrible in that sense, but on the plus side, I never had to worry about bumping into any of them. You know what it's like bumping into your ex, well he was dead so I needn't worry about bumping into him. Yeah. He was one of the first, first ones to die actually.

In addition to not expecting to face other illnesses, and not preparing or worrying about finances or care needs in older age, participants in interviews and the analysis workshop talked about being unprepared to lose people close to them who were not affected by HIV – expecting that they, because of HIV, would die first, as Sara described:

It's, what I didn't expect to do was lose people, before me. I didn't expect to lose my mum, and definitely not my sister. And don't get me wrong I didn't, when I was diagnosed I didn't think 'oh thank god for that I'm not gonna see these people die', so anything like that. But I think it hit me twice as hard, because it should be me that went.

The expectation of imminent death shaped many of the choices women made after their diagnosis and in some cases set their lives on very different paths. Yvette, a 58-year-old black African woman diagnosed for 16 years, travelled to the UK because she wanted to get on a plane and see other parts of the world before she died. Her decision to regularise her status and remain in the UK only came later, when she learned that treatment was available here. Her choices were shaped by an eventuality that did not happen, and her life now involves making meaning from those circumstances. She talked about not thinking about milestones such as turning 40:

I didn't think much about my age, because I was just thinking about my death. My age didn't bother me, it was just, my life shifted to HIV. So I neglected a lot of things.

Women diagnosed in the earlier stages of the epidemic had prepared for their deaths in different ways. Patsy had been given paperwork that entitled her to

death benefits, based on having a 6 month prognosis of survival. She railed against this and used it to fuel her determination to survive. Sara had also been given a terminal diagnosis, and talked in the workshop she participated in about the difficulty of moving past this:

Sara: the first time when I did insurance, I think it was through the Post Office and there was a section, have you been diagnosed terminally ill, which I was, so I phoned them and I sort of said 'oh I'm filling in your form here' I said 'but that was 27 years ago and I'm still here' so she said, then you're not answering the question then

Other participant: no because you're not terminally ill are you?

Sara: no, not anymore which sounds daft, you know

For Sara, the terminal diagnosis remained as a kind of spectre, affecting her decisions and outlook even as her health improved, as the finality of the diagnosis gave it a weight and endurance she struggled to overcome.

Some women talked about creating 'memory books', which women, especially those with children, were encouraged to create as a lasting memento for their families. These artefacts are imbued with significant meaning, but not the intended meaning when the women who created them survived, leaving women with the dilemma of what to do with them. Patricia, a 50-year-old black African woman, keeps hers in the attic, while Cecilia, a 51-year-old black African woman, described this conflict:

I don't know how many times I met with the social worker to write those memory books for my children. And I burned them up a few years ago, I thought I'm not keeping these things.

She found the process of creating the memory book deeply painful, as it compelled her to consider the future of her children and leaving them behind. As part of this, Cecilia gave her first child the surname of another relative, who would care for her after Cecilia had died. To this day, she and her eldest child have different surnames, which has caused her daughter some emotional distress as people assume she is adopted, but for Cecilia it was a rational choice made at a time when death was the only realistic outcome to prepare for:

But yeah those are the pains and processes and thoughts you had to go through. Just thinking, you, it just, it puts a stopgap in what you can do, especially before the drugs came along, you

just thought, 'what's the point?' Just live the day as it comes by, because you'd been told you don't really have, you don't really have that much time.

In reflecting on their lives and their feelings about the future, many women's stories evoked mixed emotions, including pride at having survived, and fears over what the future might hold. The psychological impact of preparing for death and living with an expectation of limited time ahead, was evident in many accounts, and had impacted on the choices women had made and felt able to make.

7.2.2 Places, people and things: loss due to HIV

HIV had engendered many losses for women I interviewed, from the death of friends, partners and family members to lost opportunities or derailed plans, to stigma blocking opportunities and connections.

Violeta, aged 50 and diagnosed for 28 years, described many types of loss. She had lost her hair and her physical appearance changed dramatically due to illness and HIV treatment. She had always wanted to be a mother and HIV and then a stroke meant that choice was taken away from her. She had given up work when it became impossible to manage alongside all her healthcare appointments and now felt even if her health improved she had been too long out of the workforce to realistically be able to find employment again. She felt left behind in a new narrative of HIV that compared it to diabetes and defined it as a long-term condition. She felt this narrative failed to acknowledge the experiences of people like her, who struggled daily to live with HIV and manage health problems and side effects. She also deeply regretted choices she had made when she expected not to survive. She had allowed her brother to use land belonging to her, as she expected not to live long enough to need it and he had abused her trust and taken it from her:

Because I should have sold my piece of land, cause now my land is gone. So my inheritance is gone now. I lost everything. But also because of HIV. Because, the AIDS, because I was dying, I was dying, I was dying, let them use it, they're healthy, they need to make money, I'm dying anyway.

Tindo, aged 54 and black African, had faced significant loss. Her husband had died, after which she built a new life with her children in another African country. But civil conflict emerged which resulted in her being raped, her land seized and

the manager of her farm being murdered. She fled, leaving behind two of her children, and came to the UK with her son. Having started to build a life here, her HIV diagnosis derailed her life once again:

I used to be a happy woman Jacqui. I used to have a life. I was someone. But since I was diagnosed with this disease, 2007, it's not the same. I used to drive, I used to go to work, I used to do everything which everyone would do. I try now, just eating and sleeping. Sometimes the whole day you can't talk to anyone on the phone. It's only my kids. I used to talk to people, I used to see people, they used to visit me, I used to visit them when I'm off. But I've lost all those friends, they've lost me as well.

Future plans could also be limited by HIV. Angela, a 55-year-old black British woman, discussed her desire to live abroad but felt this was unrealistic as she was too dependent on HIV treatment and care to leave the NHS. Cecilia felt HIV had limited and would continue to limit her choices in meaningful ways, from affecting her choice of career path and ability to keep working due to concerns about stress, to feeling able to manage her health.

Leila, a black African woman diagnosed for 11 years, described losing aspects of herself and her identity after HIV diagnosis, as well as family and friends. She remembered her life prior to diagnosis as happier, as she could socialise without the burden of worry about stigma she now carried.

Cause once you are diagnosed then it's like everything just fall apart, like, you know? And sometimes you just think that, oh I wish I could go back to how I was before, which, I don't know, if it can happen, or, I don't think so. Because we are not getting younger.

Stigma as a consequence of HIV caused much of the loss women described and these losses in turn shaped how women discussed and defined stigma. Feeling unable to be open with family or friends or being rejected by them was a painful experience and a barrier to social and emotional support. Looking ahead to the future, women feared stigma leading to more loss and suffering, particularly in residential care facilities. It also represented a barrier to being open and participating in non-HIV networks and communities, as Adanna, 50-years-old and diagnosed for seven years, described:

If you go, if you pass group and go outside and tell the word on the supermarket or on the church or anywhere that HIV, they

won't come back to you anymore. You'll be like the outskirts, you'll be like you have, you, you are dead, you are smelling, you are ghost, you are something. They won't come there around to you. You know. By then you will be feel isolated, by then you will, you will be so, what, you will look the way, you will have suicidal thoughts, all the time.

The idea that HIV was somehow detectable to others was used to describe the experience of stigma and being stigmatised. For Yvette, this defined living with HIV and made her angry:

Yes, because we, once you are told you're HIV you can even smell it, it's got a smell, HIV has a smell. It's horrible. You smell, like you have, like people can smell it from you. You get so paranoia, you think people can see it. You don't want eye contact, you don't, you hide. You wear so many masks. You tell a lot of lies. HIV changes you, mentally, physically. It changes you, how you see the world, you hate everybody.

These experiences were described by women diagnosed both before and after effective treatment became available. Treatment and improved knowledge about HIV did not appear to have impacted women's experiences of losses due to diagnosis and stigma.

Many women told me about terrible experiences they had due to stigma. Leila, in both a family home and a hostel, was made to comply with conditions such as using a separate toilet and not preparing food for others, due to inaccurate and discriminatory views about HIV transmission, leaving her feeling deeply upset. Sara was badly treated by doctors and other healthcare staff, including painful experiences with doctors taking unnecessary measures such as wearing multiple pairs of gloves.

HIV and the stigma with which it is treated led to loss of opportunities, relationships, work and homes. It also took loved ones directly. Many women talked about deaths due to HIV, and it is important to recognise these losses. In cultural and media coverage of the early AIDS epidemic there is often a focus on losses in gay communities in places like San Francisco, London and New York. These communities suffered loss on an almost unimaginable scale and the deaths of these men should be remembered. But women also suffered bereavement, of partners, lovers, friends from support groups and family members, both during the early epidemic in the UK and, for women from Africa

in particular, even now due to lack of access to treatment. Women described children dying recently to AIDS, and the ongoing deaths from the epidemic must be remembered when the experiences of people living with and ageing with HIV are considered.

7.2.3 Experiences of violence

Fourteen women participated in life story interviews, ten of whom talked about experiences of violence and abuse including rape, physical violence, psychological abuse and coercive control. Here, I present their experiences in their own words, and in the discussion section of this chapter I situate this within evidence of the links between HIV and gender-based violence.

Some women talked about their experiences at length while for others it was a simple mention, almost offhand. None of the women expressed or expected surprise at their experiences. None anticipated that I would be shocked by them, which was evident in some other parts of their narrative particularly around bereavements. The violence they had experienced was common, mundane even, as they described it. Indeed, some women qualified their experiences by referring to other women having worse experiences, particularly violence that was more extreme or more frequent, compared to what they had endured. This was true of Rebecca, who described a physically violent partner:

It only happened three times. And I sort of learnt, really, because if anybody said at 30 that I'd end up, that I'd be with a man that was going to hit me I'd have said 'no way'. But it wasn't regular, but it did happen on three occasions when I didn't leave him, so it gave me an insight into how, why and how women, you know, stay with someone like that.

None of the women talked about securing any kind of justice or redress for what they had experienced. Sara was one of the few to mention trying to get police involved, but found them “useless”. Violeta and Gladys had both also experienced physical violence with partners.

Adanna experienced psychological abuse and control from her husband, who claimed their marriage was illegitimate and threw her out of their marital home without warning leaving her destitute and jeopardising her visa. He took her to court to prevent her entering their home.

Michelle described her relationship with her husband as having been “quite a violent relationship”, with control and manipulation. Angela also described a controlling, abusive relationship:

But not a man that I could live with, I mean he actually was just so controlling, and really, I knew, even before I had the, while I was pregnant I just thought 'I cannot live with you'. So I said to him, you know, 'I'm going to have this baby but I am not going to stay with you' which he took very badly. And, after that, within six months of her being born, he had, was taking me to court. He contacted social services, he went to the police, he told them a whole pack of lies about how I had, was abusing my child, how my son was a danger to my daughter, how he needed to have custody and, then my life went into a tailspin that lasted for, over five years we went through that process.

Tindo was raped, and acquired HIV as a result. Alice also acquired HIV through rape:

He raped me. He was positive. I knew nothing about HIV at the time, at all, or little, the sort of general knowledge type of things. I didn't know he was positive. I had no reason to think it... And I mean I think he was just drunk, I mean it sounds stupid to say 'he was just drunk', it took me two years to admit to myself that I had been raped. I didn't, you know, it was sort of like, 'how could you let yourself be in that position?' was how I was seeing it. Which is the way most women do. So common. And there's me doing it. It took two guys who I talked about it to, who both said, 'that's rape!' And I said 'well now he didn't hit me'. 'But you said no'. 'Well I couldn't get him off of me'. 'That's rape.' So I thought, I guess you tend to think that rape involves really brutal physical violence as opposed to you being held down, you know, and not being able to, to stop what's happening to you, happening. I couldn't believe it was happening. I couldn't believe that I couldn't stop it. It was just mind-blowing, to find myself in that position.

Yvette acquired HIV through rape, and also suffered many other instances of violence including child abuse, coercive control and domestic servitude.

Violence was not a question or topic in this study, but emerged in women's stories as part of their lives, that had impacted on them in different ways. As a small qualitative study, the numbers cannot be extrapolated from, but the prevalence suggests the importance of thinking about violence and its impact when considering the needs and experiences of women ageing with HIV.

7.2.4 Experiences of bereavement and trauma

Women also shared traumatic experiences and bereavements that were not linked to HIV. This included childhood experiences in war and conflict zones, as well as abuse, and deaths of loved ones. Often, women shared these stories in reflective terms thinking about how they had come through them and what they had learned from them. For example, Cecilia as a young adult was caught up in civil war in Uganda:

... I also went through quite a traumatic experience when my father was murdered, and by then I was in university so I was in my early twenties, maybe, maybe 21, and that was the time when the Lord's Resistance Army was going through Uganda, and everything, so he was murdered around that time, and it did affect the family, but I think we all managed to come together.

Patricia was also affected by the war in Uganda, which led to the death of her stepfather and left her mother trapped in a distant town and unable to return to Patricia and her younger siblings who she ended up caring for while struggling to study and to survive financially.

Angela described how she felt she had survived racism and the early deaths of her mother and brother by finding her inner strength:

I grew up in an all-white town, we were discriminated from the day I knew anything. That's what I know. I know exactly what those eyes are. You don't know what, you, if I put you in my place you will not survive. It's actually, if you know how to survive it it's actually a skill that will stand you in good stead.

Rebecca described an “idyllic” childhood that gradually fell apart due to her father’s alcoholism, leading to the end of her parents’ marriage, followed two years later by her mother’s death and Rebecca being taken into care. She went on to struggle with drug addiction and was finally diagnosed with HIV in prison.

These experiences of trauma and loss prior to HIV were as important in women’s stories as HIV itself, and were an important outcome of the open, life story interview approach which allowed a wider frame than a semi-structured interview would have created. Ageing with HIV is not just about HIV, but also about the accumulated experiences of life, including traumatic events and the lessons learned through them.

7.2.5 HIV diagnosis experiences

Diagnosis interrupted women's lives, plans and understanding of themselves. It was often met with shock, and sometimes anger. Few women I spoke to had anticipated their diagnosis. It had an immediate, disruptive impact on their lives. Diagnosis as an event was a distinct topic in women's narratives, separate from living with HIV, which gradually emerged after diagnosis as women learned to assimilate HIV into their lives and sense of self. As a major life event, diagnosis featured in all the narratives and workshops, and was often described at some length. It is not possible in this thesis to do justice to all these separate stories, but I highlight a selection as examples.

Gladys, a 53-year-old black African woman, had been diagnosed for four years and was the most recently diagnosed interview participant. She had struggled to cope with ill health and stigma at diagnosis:

So they told me I'm positive. And at first I really didn't believe I am, so I was really, shocked to hear the bad news and what I did from there, I was, my doctor advised me where to go for help, regarding my situation, and I was referred to the [HIV clinic] where I went, and I registered with them. I booked an appointment to start my treatment, and I didn't get my treatment at the first, the day I went, the first day, because they told me since it is very early diagnosed, there's nothing they can do, and they, I can't have any treatment because, I think it was because of the, the, it was too early and it was really my first, I was just early diagnosed so, so they told me I will stay like, about, maybe couple of months and then they'll start treating me. So from that time I started feeling a lot of pains all over me, my body, my legs, and I couldn't even cope with that, it was really painful, and there's nothing they could have done.

Rebecca, a 64-year-old white British woman, had been diagnosed for 30 years, the longest of all the participants. Her boyfriend was diagnosed first, and this and growing news stories about HIV among drug users had led to her worrying about HIV, and feeling like she would inevitably be affected:

...I got myself arrested on some silly, petty, drug related offence, and I was in Holloway, and I, I think, I told them I'd had a test, thinking oh maybe they'll give me bail. So, but they didn't, so I got my results in Holloway prison, which was pretty dreadful. So, I get called into an office, and, I get called into an office, and, and I just got told, I mean the first thing I did was say 'can I have a cigarette?' Because it's, a chance to get a cigarette. And they

told me, and my first question actually was 'well what about children?' I was 36, I was 34, I was 34, and it was January of 1987. And yes for some reason, not that I'd sort of been thinking, you know, I think subconsciously I always thought maybe I would have a child one day. But my first question was 'well what about children?' And she said 'no, you'd die, and the child would die.' As we know that's not true anymore, but at the time that's how it was thought. She didn't really say much else, I just, asked for another cigarette. And then I got escorted back to a, segregated cell, a single cell, and so I wasn't allowed out. I was in there 23 hours a day. My food was passed through the hatch.

Angela received her diagnosis 26 years before her interview, and described the immediate traumatic impact it had:

So, yes, I was diagnosed back in 1991. January, 1991. I, I kind of knew straight away that something was wrong. I mean I can remember that like it was yesterday, that it was so traumatic that, such a shock, I mean I couldn't believe that I could, it could, I could possibly be in that position. I'd just started a relationship with a boyfriend, we were only about three months in, [laughs] and to, you know, he came and told me about his ex-partner who was, was taken in hospital. She subsequently died. I was just like, you know, 'don't be ridiculous'. I was in my twenties, it was like, there's no way it could be me. And then, you know, obviously the result came back and it was me. And it, it was, you know, absolutely... What can I say? You know, for me the diagnosis just totally attacked my sense of self. I just don't, anything that you thought and assumed about yourself, just is no longer a certainty. Things that you never questioned.

Alice was sufficiently ill during seroconversion to be hospitalised, so was diagnosed very early. Having only recently been tested after being raped, she agreed to another HIV test but felt sure it would again be negative. She said:

And, I was told that I was HIV positive. I remember only two things now from the conversation, or did at the time, one was me saying 'I can't die my daughter needs me'. And Ian, the HIV nurse, saying 'you could live to be a hundred'. That's it.

Yvette reacted with shock and anger to her diagnosis, and struggled to understand how she could be affected. Cecilia was told she was going to die, and struggled to keep herself and her family together.

All the women I spoke to described similar reactions of shock and fear, including expecting to die as a result of having HIV, even when diagnosed after treatment was available. This demonstrates the lack of knowledge about HIV that women

had at the time of their HIV test and diagnosis, which greatly contributed to the trauma of receiving the diagnosis. It was often only when accessing HIV support groups and finding connections to the HIV community that women described feeling able to reconcile to their diagnosis and to understand that it was possible to live well with HIV. This enabled them to live on, though often a life on a very different path to before their diagnosis.

7.2.6 Living and ageing with HIV: the everyday reality and uncertainty of long-term HIV

The majority of the experiences described in this chapter so far took place earlier in the lives of the women sharing their stories, who used the life story interviews as a space to reflect on these challenges. However, many of the women were also facing challenges in the present, including 'survivor conflict', and the everyday challenges of living and ageing with HIV. I combine the two as ageing itself is not a separate process. Though women described fears about the future as they aged further, these were often an extension of existing challenges and concerns. This included staying well, managing different health conditions and co-morbidities and coping with health problems. This all existed in a framework of uncertainty, including inconsistent symptoms and health, difficulty in ascribing symptoms or health problems to HIV, normal ageing, other health problems or treatment side effects, inadequate information and support that met their needs, and concerns about long-term health.

Many women, like this participant at the AHPN workshop, described struggling with multiple health conditions and challenges:

I have osteoporosis, and also arthritis, and I had a mini stroke, and I have problems with my right knee, at times it swells, and when you go to the hospital they tell you that it's wear and tear.... Now so, you don't know what to do, you don't know who to turn to.

Other health conditions that women had or were experiencing included carpal tunnel syndrome, osteoarthritis, breast cancer, cervical cancer, abnormal smear tests, depression and other mental health conditions, high cholesterol, anorexia, stroke, joint and mobility problems, postural hypertension, auto immune conditions and difficulty sleeping. Women often had multiple health conditions in

addition to HIV and described the difficulty in managing all of these, though this was not the dominant narrative in most stories. Rather than other health conditions as such, by far the most common health challenges women discussed were pain and forgetfulness. 'Aches and pains' dominated discussion at the AHPN and Food Chain workshops, where participants shared experiences of this as a constant and increasing aspect of their lives.

Patricia struggled with severe pain which was impacting on her life, ability to work and wellbeing. As well as the pain itself, she struggled with the lack of a definite cause or diagnosis of the pain:

Except now, I think I'm, if I only I could be in good health again, I'm battling with pain now, maybe whether that pain is the medication, the HIV, the old age that is creeping in, I don't know. But to tell the truth I'm, my health is every other day I'm not well, and I, I feel its hard work now.

Pain and pain management was a daily struggle for many participants and warrants further attention. It was difficult to separate the extent to which it was HIV itself or pain linked to HIV (linked at least by the participants, if not proven medically) that had a limiting effect on women's lives when they talked about issues like being unable to work or socialise, or relying on support groups. Often the support of the HIV community was prioritised because of the understanding it provided, and this included for many women understanding of the limitations imposed by living with pain.

Forgetfulness and memory problems were also a frequent theme, and many women feared these worsening as they got older. Anticipating older age was often couched in fear, particularly around the unpredictability of how their health and physical and mental abilities would deteriorate. Women often anticipated a future where they would be more dependent and less able to manage.

While women often anticipated a trend of decline over time, in the immediate term the greater challenge was inconsistency. Women talked about being fine one day, and unable to get out of bed due to pain the next, and struggling with treatment side effects that were both debilitating and erratic, such as diarrhoea, which was very common. The sense of being among the first to experience these challenges, whether that was to do with diagnosis, treatment or old age, and this

entailing limited information about what their future would look like, dominated for many women, who struggled with their trusted HIV consultants and clinics being unable to provide definitive answers. Even women who were well-informed and engaged with research noted that there were more questions than answers, as Alice summarised:

I do worry about what my health will be like, because anything I now have will be exaggerated. The other thing is that, there is this peculiar thing that came into my head because of doing this interview, which is I'm one of the oldest people who's got HIV. I'm part of the cohort of the oldest people living with HIV. Therefore how we are going to be isn't known, because we're the first. I'm not someone who's been on medication forever, therefore I'm not somebody who will have those problems. I can't be predicted in that way. Because I'm not part of that. But how I'm going to be at all is not predictable, because I'm like a pioneer, because of my age and lack of medication, and so on. And saying, like being a pioneer, but I like to have information, knowledge is power, I want information. That's why I go through research, because I want to know what the parameters might be, so I can at least think about it.

The existence of scientific debate and a lack of clarity and certainty had a palpable impact on women's wellbeing and level of worry about the future. This was compounded by the challenges in explaining symptoms or health issues, which could be linked to HIV or HIV treatment, or be an outcome of normal ageing or due to other health issues. Patricia described struggling with health problems that she could not control or understand, and with not knowing how far HIV was responsible for these. This combined to increase worry about ageing with HIV and concerns about the future.

7.2.7 HIV treatment: managing and meaning

HIV is not directly experienced in daily life, but is symbolised by treatment which is a daily reality. All but one woman taking part in this study was on HIV treatment, and the reality of life with antiretrovirals, both taking treatment and managing side effects, was a dominant theme. The relationship women had with treatment was complex, as many women expressed gratitude for access to it and improvements over time, yet still struggled with the challenge of taking pills every day, and living with debilitating side effects.

It is usual to hear modern antiretrovirals described as having limited side effects. While severe side effects have been minimised, many women I talked to dealt with side effects that limited their lives in various meaningful ways. Women often described this as just 'how it is', and were reluctant to complain. Alice described this same perception she had gained through her advocacy work sharing research updates with people living with HIV:

One of my big gripes is how under-reported side effects are. There is a natural determination to be compliant with a clinician, particularly in people who don't have English as a first language, particularly in particular African cultures, because, there is an innate respect for a doctor, there is a gratitude for the fact that there is a medication and that they have it, and that they're allowed to. And also, a received information amongst, you think about this and just see how much you pick out from people, amongst the whole HIV community, which is that having diarrhoea, not sleeping, getting headaches, feeling low, is what you have to go through to survive. And you will have it to a certain extent. You will have it more, or you will have it less. If you actually raise, with a group like that, as I do, the problems of having diarrhoea, as in, you've got to get from A to B and find a toilet on the way. The number of, you know, I, if you just say 'has anybody ever had this?' Whole room. Have they reported it? No. It has to be worse than that, or you don't report it.

The prospect of living with HIV treatment for the rest of their lives was intimidating for some women, who talked about reaching a time where they might be able to stop treatment or move on to something better. Tindo said:

If someone can sit down and tell us about what we're going through with our tablets, for how long we are going to have those tablets, is there any time we will be stopped to have tablets and then we can still move on? Is there any way they are going to give us something different? Because as far as I know, those tablets have got side effects. Are they taking us to the end of our life or will we have something better for our life?

She described struggling as she did not understand the medication or why symptoms like pain were worsening despite taking the medication properly. Antiretrovirals were understood as necessary but a site of limited understanding and a cause of worry. As Tindo said, *"I just swallow because I want to survive. I don't even know what's inside them."* Patricia described initially feeling well on medication and experiencing a marked improvement in health, but as she aged, pain became a bigger problem and she now questioned if the treatment was right

for her and working well. While her CD4 count and viral loads were good, this was not a tangible outcome for Patricia, who felt she needed a psychological motivation to take her pills every day that these biomedical markers did not provide. She described waking up at 5 o'clock in the morning so she could eat early enough that she would be able to use the toilet multiple times before leaving the house, to enable her to safely travel to work. Pain, chronic diarrhoea and sleep problems were the daily reality of treatment so taking them was becoming psychologically harder to manage.

The burden of side effects and worry about treatment interactions and polypharmacy was significant for many women. Side effects like diarrhoea are often categorised as mild, but as a daily reality are a significant burden. Treatment becomes contested, as it means both survival and ill health, and the former is more long-term and abstract while the latter is real and palpable now. Some women talked about hopes for better treatment in the future or even to stop taking treatment, particularly as they got older, and these hopes should be recognised as treatment advances are pursued.

7.2.8 Transitions: ageing and menopause

Ageing was often conceptualised as transition, moving from one state to another, generally involving decline. This was preceded by the transition of the menopause. Women expressed worry over the menopause, from knowing when it was happening, to managing side effects and moving on from it.

The menopause was likened to HIV itself by some women who experienced it in a similar way: threatening identity, impacting on feelings of desirability and interest in sex and challenging their sense of self. There was also a feeling that, like HIV, menopause demanded secrecy, apart from within groups of other women of a similar age, again leading to a preference for support from peers. Problems with sleeping, 'foggy-headedness', night sweats and mood were described by women who had experienced menopause, while women who had not yet entered the menopause transition worried about the same.

Some women, including Tindo, had not discussed menopause with any medical professional, and she described only recognising her menopause because women in her support group described their menopausal symptoms and she

recognised her own experiences. Gladys, alternatively, had support from her GP, who prescribed her hormone replacement therapy (HRT) to help manage her menopausal symptoms:

So I think I went to see my GP, and my GP said to me that I think I have an early menopause, so that, and she told me there's something she can give me for, for that. And what she prescribed was replacement, HRT, and I was in the HRT replacement for three years, yeah, because I used to have lots of headache, I used to have, sweat a lot at nights, yeah, sometimes I don't even sleep, lack of sleep, I can't sleep very well, yeah. So it was, that was the time I was starting my menopause, yeah, and I found my body changing a lot, feeling very tired and I'm weak. I can't sleep at night, yeah.

These experiences indicate a need for more information and support about menopause, including normal age of menopause and recognising symptoms, as well as information about and access to HRT.

7.3 Discussion

'Nevertheless, she persisted'. A phrase used initially by a man trying to remind a woman of her place, and taken up instead by women to describe the experience of carrying on in the face of challenges, speaking up when others would silence you. I thought of this phrase a great deal as I transcribed the interviews reported here. Each women had in her story experiences of loss, trauma, and challenge that could have been enough to break them. Instead, they carried on. Persistence defined these narratives. Not an overcoming, or a triumph over adversity, but continuing, picking up the pieces and building something different but still valued.

Ten years ago, I took part in a sponsored skydive, organised to raise funds for a charity. I did not really want to do it, and tried to back out, but in a tandem skydive, you are strapped to a harness attached to a professional who in my case was much taller than me. When he stood to jump from the plane, I was a foot clear of the floor, and unable to stop him, despite my best efforts. He jumped, and so did I. For a minute of freefalling, everything was terror. Then, the parachute went up, and a surge of adrenaline overtook everything, and the only feeling left was wonderful. A few years later, I took part in a charity abseil, at Battersea Power Station, expecting a similar experience. That was a misjudgement. In an abseil,

you jump over the edge, but there is no parachute. There is just you, and a rope, and your two feet, and you climb. And you keep climbing (and in my case, crying and panicking) until you reach the ground. I thought of this often, too, as I transcribed and analysed these interviews. The experience of diagnosis threw women over the edge, but there was no parachute. Instead, they just had to keep climbing. And the HIV community and the solidarity and lived experiences of other women who had also been thrown over the edge and kept climbing, was the rope that showed the way and provided something to cling to, to keep from falling.

The stories women told constructed life as an accumulation of trauma and sadness, but also, more so, as a gathering of joy and meaning, the focus of the following chapter. Women persist, and in doing so each woman I spoke to had built lives of meaning and connections of value. Some were struggling more than others, and the bleakness with which many women surveyed the future is deeply concerning. Much more support is needed that recognises the complexity of ageing with HIV and the challenges women have experienced outside of HIV that impact on their ability to live well.

Women diagnosed before effective treatment became accessible talked about a unique set of needs and experiences that are not adequately understood or addressed. Living with HIV is an ongoing, evolving experience that brings challenges that can be hard to reconcile with simple constructs of 'survival'. What HIV means changes with time and age, as does the meaning of HIV treatment and the relationship women have with it. Physical changes and experiences including the menopause and side effects have an ongoing impact on women's lives, but many women described a lack of support and information to manage this. Side effects are limiting women's lives and wellbeing, but are under-recognised and potentially under-reported.

Violence, in all its forms, was a common experience for women participating in this study. It is also increasingly recognised as commonly affecting women living with HIV. A recent study conducted in the UK, which I co-led, found 58% of women living with HIV responding to an online survey had experienced gender-based violence (Sophia Forum and Terrence Higgins Trust 2018). A study conducted in a London HIV clinic in 2013 found over half of women attending the

service had experienced intimate partner violence in their lifetime (Dhairyawar, Tariq et al. 2013). Another clinic based study found over 40% of women attending had experienced intimate partner violence (Rita, Blume et al. 2014).

Here too, women persisted. Their narratives were of coping and continuing, shaped by recognition that violence is common and their own experience could have been worse. Hearing and transcribing these stories was difficult. The time in which I transcribed the majority of these interviews coincided with the emergence of the #MeToo movement. On the news, on Twitter and in my research, women were saying #MeToo. The lesson of that movement and of these stories is not that men with power will use it to abuse women. We all already knew that. The lesson instead is that violence is pervasive to the extent that it hardly warrants mentioning, and so often is not discussed.

In an early draft of this thesis, I discussed experiences and identities my participants were likely to have and what I would and would not share, and how this might impact on the research. I said I had not experienced gender-based violence. That was not true. In a later draft, I said I had not experienced 'more serious' gender-based violence. An odd construction I would never apply to the stories told by my participants. One of the interesting things about the PhD as a process is how long it takes, and how many drafts and versions it goes through, while readers will almost always only see the final one. This obscures some of the process of the research, and the impact on the researcher. Hearing these stories, transcribing them, writing them, had a profound effect on me as a researcher and as a person. #MeToo. Recognising that violence is overwhelmingly likely to be part of women's stories is critical to understanding them, and to ensuring that the support and services in place for women and the research they are invited to participate in speaks to them and their stories.

7.4 Analysis

Women's stories evoked persisting, rather than resisting or overcoming, problematizing narratives of HIV as being controlled, triumphed over or the 'making of' a person. Instead, women spoke about accommodating HIV alongside other traumas, losses and disappointments and working to centre

positive experiences, community, and belonging in order to live well and to continue. In this chapter, I have focused on the difficult experiences women have faced in their lives. In the next chapter, I focus on the community, relationships and belonging that women described as sustaining and supporting them through these challenges, and in the subsequent chapter, I present the assets and resources that supported women to cope with HIV and other challenges.

The findings presented in this chapter respond to two of the research questions I set out to explore:

- How are these experiences mediated by gender, sexuality, ethnicity, migration status and experiences, or other factors?
- How have women adapted to ageing with HIV, including experiences of age-related conditions and other co-morbidities, home and residential care, and economic and social issues?

Women's experiences are impacted by gender and by gender-based violence, as a cause of HIV, a consequence of HIV, and unconnected to HIV. This shapes women's sense of belonging within a community of women and, alongside other losses and traumas, can either underscore inner strength and ability to cope, or weaken it, especially where support is lacking. There is limited focus on violence in regards to ageing with HIV, and the empirical review (presented in chapter two) found no literature on this topic. The prevalence of experiences of violence indicates a need for more research to understand how violence impacts women's ability to cope with HIV. In particular, for women who acquired HIV through violence, as three women in this study described.

Migration played a significant role in mediating women's experiences. The uncertainty and limitations imposed by unresolved immigration status, including the inability to work and travel, limited women's options and sense of control in their lives. In the case of bereavement, for some participants, grief at the loss of a loved one, often a child, was made more unbearable by being unable to attend the funeral or visit the grave. Other women were made more vulnerable to violence or exploitation by their immigration status. Migration appeared to be a greater factor than ethnicity, though this perhaps indicates how interlinked the two are for many women.

Time since HIV diagnosis emerged as perhaps the most impactful mediator of women's experiences. In many ways, women diagnosed recently with HIV had surprisingly similar experiences, describing the shock of diagnosis, fears for the future, stigma and struggles with treatment and side effects. However, women diagnosed before effective treatment described meaningfully different experiences in adapting to a terminal diagnosis and adapting to an unexpected older age when they survived.

'Survivor conflict' is a concept that captures the complexity of persisting despite HIV and other challenges, making meaning and building connections while reconciling the losses that HIV engenders and the psychological struggle of unexpected survival and unanticipated older age. "I'm still here" echoed through many women's stories, as an expression of surprise, achievement and also loss. Preparing for dying had exacted an emotional and psychological toll that continued to influence women's lives and choices, from feeling unable to plan more than a couple of years ahead, to continuing to live with accommodations made at that time, such as Cecilia's daughter's surname,

Diagnosis is often experienced as an interruption to and displacement from existing lives and plans. Adapting to HIV involves constructing a new narrative and life journey and accepting this new path. This can include positive additions, especially belonging to the HIV community, but brings with it challenges including lost opportunities and relationships.

Women's adaptations to ageing with HIV were limited by struggles with side effects and accessing adequate information and support. Many women struggled to manage co-morbidities alongside HIV, and in particular, pain and forgetfulness impeded women's ability to live well. Women often felt under-informed and under-supported regarding the menopause, and the additional uncertainty introduced by this transition compounded the ongoing uncertainty surrounding HIV, HIV treatment and other health conditions. The long-term burden of ill health was cumulative, and further compounded by side effects, which for many women were debilitating despite all the advances made in treatment. This resonates with findings from a global survey of women living with HIV, which found side effects

were experienced by 88% of respondents to an optional section on treatment, with women reporting a mean of four side effects (Welbourn, Orza et al. 2016).

In the empirical literature review presented in chapter two of this thesis, I identified nine interlinked themes. These were: social networks and relationships; intimate partners, family and friends; mental health, wellbeing and coping; care and social support; loneliness and isolation; stigma and discrimination; health needs and co-morbidities; socio-economic and practical issues; disclosure; and, ageism. Reflecting on the data presented in this chapter, it is interesting to note that ageism did not emerge strongly in these women's stories. Loneliness and isolation was a challenge for some women, but for many it was mediated by HIV community, and by family and friends. Women who described more loneliness and isolation were often migrant women, and often highly dependent on HIV support services. This indicates, firstly, the critical need for continued resourcing of these services (which as reported in chapter five, is in some jeopardy) and secondly, the need for support to develop social networks and social support outside of formal services. Women diagnosed early in the epidemic often described a merging of their social networks in and out of services, and this could be explored further to consider how more recently diagnosed women could be supported to do the same. The following chapter explores further the role of community and social networks in women living with HIV's narratives.

8. MAIN FINDINGS: THE PERSONAL IS POLITICAL: COMMUNITY AND PARTICIPATION

In this chapter, I explore participation and personal connections, including belonging to an 'HIV community', and how HIV interacts with personal communities and relationships. As with the preceding chapter, following a short introduction I present findings drawn from life story interviews and participatory creative workshops, organised by theme. This ensures women's voices are prioritised. This is followed by a short discussion, bringing together the themes presented and my own reflections, then the final section presents an analysis of these findings in relation to relevant literature and earlier parts of this study.

8.1 Introduction

In the stories women shared, belonging to and acting within the 'HIV community' was described in terms of both receiving and providing support, predominantly defined through individual-to-individual ties and connections, a belonging that supports resisting and reconfiguring HIV and the social burden it implies. Advocacy functions within the political act of living a stigmatised life without shame, and telling stories that change minds, with research as a tool to facilitate this alongside other advocacy activities. Through their life stories, older women living with HIV discursively constructed 'participation' as fundamentally about personal connections and interpersonal relationships.

HIV is a bridge to a community of identity that is deeply valued. Outside an HIV-specific network, HIV is also, contrastingly, a barrier to relationships with intimate partners, friends and family. Living with HIV augments connections, possibilities and relationships, interacting and intersecting with other aspects of life to alter in greater and lesser ways the social experiences of older women living with HIV. For example, the relationship between HIV and motherhood is complex, as is women's relationship with motherhood as both experience and identity. In some cases, migration as a result of or influenced by HIV status presents a physical barrier to active motherhood and generates complex, conflicting emotions. For others HIV prevented them from having children, while others chose not to become mothers, and feel invisible in a wider narrative that constructs women living with HIV as mothers first.

Participation and personal connections are shaped by talking about HIV: not the event of disclosure, but instead a complex ongoing process of keeping secrets or opening up. HIV itself is a personal and a political experience, as a health condition experienced physically and as a social experience which, through societal stigma and through participation in an HIV community, becomes political. The feminist mantra 'the personal is political' is borne out in the stories of women living and ageing with HIV as a consequence of the political nature of HIV and the response to it.

8.2 Themes and findings

8.2.1: Belonging to an HIV community – supporting, being supported, resisting

Living with HIV provided a connection to an HIV community, formed through shared experiences of diagnosis and living with HIV. This community often emerged in formal services, which for most women were their entry point to the community and a space in which they felt safe, supported and 'at home'. The value of this place of belonging was described in many of the life stories women shared, though there were also concerns about challenges for or within the community, including loss of funding for formal services, changes to the community over time and stigma within the community.

Accessing and receiving support was a dominant theme in many of the narratives shared by women taking part in both workshops and interviews. Support was accessed through formal support services, but this was not generally distinguished from community, instead being the structure within which community functions. In the workshops, one stage of the body mapping process was to identify where participants accessed support. The vast majority of women listed at least one and often multiple HIV-specific support providers.

For many women, attending support groups in the period following their diagnosis with HIV was invaluable in gaining access to advice and information as well as the opportunity to meet others living with HIV. Patricia, a 50-year-old black African woman, described how, after her diagnosis 21 years ago, she had felt isolated and frightened until she took up advice from her clinic to attend a support group:

And well, surprise, surprise, I went in, in this group of women and I, I just felt like 'oh my god, these are my, this is my other home.' Everybody was like smiling, welcoming, sharing. I, I don't remember I talked much apart from just saying 'I'm new to the group, I've just found out and I have a baby' and they're like 'wow', so a couple of women were like, 'oh so am I, I have two children, I have this...' Some were pregnant. And I'm like 'oh my goodness', sometimes I want to feel sorry for them like, 'wow are you not worried about your baby?' and it's like 'well what can you do? But you know I'm getting support here.' So for me, meeting those women and coming to the support group was like a medicine, it was like somewhere where I felt like 'wow I can leave my burdens here'.

Like Patricia, many participants who were diagnosed early in the HIV epidemic, in the pre-treatment era especially, described the invaluable support offered by services that created a safe space to discuss their fears. Not all experiences were wholly positive, Angela a 55-year-old black British woman, described being shocked at the visible ill health of other support group attendees after her diagnosis 26 years ago, which discouraged her from taking treatment initially. However, she still felt that she been helped to cope and access information by attending the group.

Diagnosis was also associated with needing support for more recently diagnosed women, who did not feel they had otherwise been provided the information and support they needed. Alice, a 68-year-old white British woman, was diagnosed in 2008 after a period of serious ill health:

I was terrified that I was going to die. Now, everybody says now 'well why on earth did you think that? Didn't anyone tell you?' And, no actually they didn't, not really, not at all. And I read everything I could read but it wasn't like you could read what you can now read. If you think about it, it was 2008 that the Swiss statement was published, and it was controversial and thought to be untrue. I went to Body & Soul, Body & Soul was for me fundamental in changing my perception of myself and my perception of my future. The first time I went there I looked at everybody in the room and they're all smiling, and they're all happy, and they're all chatting, and I just thought 'how the fuck can they be happy? How can they be happy?'

Alice's story illustrates how public knowledge about HIV has not kept pace with progress, and women diagnosed with HIV often hold outdated, inaccurate ideas about HIV. Community provides a space to explore these fears, find accurate

information and meet other people living with HIV who embody the principle of HIV as a chronic condition by being well.

Beyond diagnosis, other support needs were also met through the HIV community. Adanna is a 50-year-old black African woman, diagnosed for seven years and struggling to resolve her immigration status after the breakdown of her marriage and loss of spousal visa support. For her, support services are a lifeline in providing access to social support, food, clothing and advice. This need for support goes beyond the initial diagnosis period, and indeed for many of the women I interviewed, support groups became an ongoing part of their lives. For Yvette, after 16 years living with HIV, attending groups was still important, but she took a directive role in ensuring discussions were focused on relevant topics such as new medications or side effects she was experiencing.

Women's need for support changed over time, as they accepted or adapted to their HIV diagnosis, and as other challenges in their lives arose or were resolved. But the sense of belonging to an HIV community, and finding in it social, emotional and practical support which could not be easily replaced by other social connections, remained. In many women's narratives, this included a shift from receiving to also providing support, whether in a professional role in the HIV sector or informally in friendship networks or support groups. This transition was often described in positive terms, as a marker of growth and 'giving back' to a community, in a cyclical process of a more experienced person helping a newer community member. It also created challenges for some women, if the transition created barriers to accessing support they needed themselves.

Some of the women had moved into professional roles in the HIV sector, as peer educators, leading support groups or in managerial roles. Angela described her work with an HIV charity as rewarding and opening up opportunities she never expected to have access to. For Patsy, a trans woman living with HIV for 24 years, working and advocating for others living with HIV, both women and trans people, gave her hope for the future:

But what gives me hope on a grander scale is the work that I see a resilient group of women doing around me and that I, I feel, you know, genuinely, very kind of lucky to be part of, in this period of time. Because you know, it's a period of time when it

would be really easy for people that have never been helped to get completely lost i.e. women in the kind of HIV debate, because as we move on to those kind of notions of undetectable, PrEP et cetera, you know, there is still a whole swathe of people for whom they've never had kind of, they've never had the hope of, of community, of HIV community.

Outside of a professional role providing support for other people living with HIV, other participants still felt a desire or responsibility to do this in an informal or voluntary capacity. Yvette, Tindo and Patricia, all black African women in their fifties, shared their aspirations or experiences in providing information and support to others, while Alice talked about her commitment to becoming an “expert patient” and sharing research developments to service users at an HIV charity she supports.

Taking on the role of support provider also brought challenges. Cecilia, after her diagnosis 26 years ago, moved swiftly from attending a support group to a staff role in that same organisation, then a career that included commissioning HIV support services. In her professional roles, she had not disclosed her HIV status, so felt unable to access formal support services.

And if there was a place to go, maybe, but then you, it's a bit too late now, because I've not been for so long, it's that fear of the unknown. What am I really going to walk into now? What am I going to meet there? What are we going to discuss? Do I have the time? You know. Do I want to do this? I think that part of me that used to attend groups a lot, I've parked it, and I've never thought about exploring it again... Because most of the groups I've been to, there could be one-off topics, but then the women that are going to those groups, as a provider when I walk in, they have more pressing things, and they'll only address their health issues once all these have been addressed. So if I don't have housing, if I don't have food, why should I start talking about menopause? It's not interesting me. I want to have a job, I want to have a house, I want to be able to feed my children. I may be deported tomorrow. So those are the things I want you to talk, to listen to me, and understand, and even if you're there just to listen, or maybe do you know a lawyer that can help me. I'm not here to talk about menopause, or diabetes or obesity, that's not my priority. So my, that's why I said my needs, are quite different from a, a woman ageing with HIV who maybe was diagnosed 5 years ago. Depending on how long she's also been in this country, depending on her own journey, it's very, very, you know, it is different, yeah, very, very different.

The sense that the needs of other women were greater, more complex and more challenging, resonated through other narratives as well. This demonstrated a desire for a greater variety in support and services. It also illuminated an important thread running through many of the stories women shared, about changes in community over time, at both the individual level and overall. Diagnosis brought a similar set of immediate challenges and support needs, which were shared to a great extent despite other differences between women. This was especially so in the early days of the epidemic, where all women faced a similar prognosis regardless of other capital. However, once treatment became available and women faced living long-term with HIV, other factors became more influential. Women like Cecilia, with social capital, an education, a professional career, faced a very different set of challenges to women like Adanna, facing uncertain immigration status, a relationship break-down, and poverty. HIV is no longer the leveller it once was, and this was reflected in women's changing sense of access to and entitlement to support. As Cecilia described, her problems felt smaller and less urgent than those she knew other women experienced, which has become a barrier to accessing support from this community. It is important to avoid artificial dichotomies in this analysis. Alice had a successful career, and was building a life in another European country before she acquired HIV. Her diagnosis was accompanied by a loss of savings and income, and a return to the UK to difficult financial circumstances and serious ill health. Alice was given support from an HIV charity in accessing benefits, managing at home, with food and practicalities as well as the space to benefit from information and learning from others. Her desire to contribute to the HIV community and support others was driven by her feeling of belonging to a community that had supported her.

Financial, practical and immigration support were accessed and valued by many participants. However, some women felt that services were not fully meeting their needs, including for emotional support and social activities. This indicated a dependence on formal services, which contrasts with normalisation discourses of HIV. Many women depended on HIV organisations for broad needs far beyond the support group. In the workshop hosted by AHPN, participants suggested that because services are not designed for older people and those who are on long-term treatment, not all their needs were being met. Similar views were expressed

by participants at the Food Chain workshop, who described feeling left behind by a new narrative that framed HIV as a long-term condition easily managed with treatment, and felt they were not able to share their difficulties around pain or side effects without being judged by other attendees at support groups. Tindo, in her life story interview, described her sense that as a 54-year-old women, she could not gain support from groups with mixed age participants:

And the groups we are meeting, mixing with young children, to me it doesn't, it doesn't make sense. I'm a very shy person, I'm a very quiet person, I don't talk. And there's no way I can talk to those, because as soon as you come out, they can tell the next person. I don't think they have all that confidentiality to say, whatever we say here it will end here, they are too young, yeah.

In addition to groups specifically for older people, participants talked about a preference for more social, fun activities. Suggestions included practical and skills-based courses, day trips, and dances. The Joyful Noise choir run by Naz for people living with HIV was cited by Rebecca and Michelle as an example of an activity that had impacted positively on them.

Many women felt that cuts to funding and changes to commissioning meant there were now fewer services and they were becoming harder to access. At both the Food Chain and AHPN workshops, participants described fears that future cuts could further reduce the amount and type of support available. Changes to the location or provider of services were also a source of concern, due to the emotional burden and challenge of having to start again at the beginning. One woman at the Food Chain summed up her view that

There used to be one [support group] but now these days because of the cuts you cannot get funds, funding, and it is putting us down because we don't meet anymore, we are just locked indoors, we don't socialise, there is no way we can meet men, unless if we go in those groups so you just, you know, like we are just waiting to die. No life. Just eating, going to the toilet and that's it. Very, very depressed.

Violeta, a 50-year-old European woman, felt that as a white woman with no children, the support that was available often did not meet her needs, as the experiences of others in support groups did not resonate with her own. She also missed the range of services she had access to earlier in her HIV journey:

So, and yeah, and I feel left out now when my 30 something years of HIV, and when my 50 years old being a person, and a woman, because when I found out about my HIV and everything, there was so many services, to help you through, you know, to go through that. And it was like so much counselling and massage and places where to go, and even if you felt lonely you could go like Monday to Positively Women, Tuesday to Body Positive, like, Wednesday to the Lighthouse, you know, so you felt like, you had places where to go, and cry or maybe just sit there and just being you. You could talk to other, other people.

In the context of cuts and reductions in HIV support services, women described depending significantly on HIV clinical services. The support provided by their HIV consultant and HIV clinic was highly valued by participants, especially as it was consistent, and less affected by cuts than third sector services. Though some described negative experiences with GPs, women who discussed their HIV-specific care were generally very positive about it. Tindo, for example, said that

...my consultant is my life. If it wasn't for him I think by now I would be dead. I have time to talk to him. He listens to me. He understand me better.

Community is not just about support, and meeting specific needs. While women often 'entered' the HIV community through a support group, the value of belonging to a community went beyond support. Sara, a 55-year-old white British woman, and Patricia, a 50-year-old black African woman, both described the safety and understanding that belonging to the HIV community provides. For Sara, the sense of belonging and togetherness was key, with all people living with HIV. Patricia described the value of being understood, and the safety she felt compared to other social connections:

You can build your own community, create your own community, other than the normal communities that are supposed to be there. Especially the normal community, sometimes if they don't know, if you're living with a, a secret disease that you don't wanna share with people it then becomes difficult to explain yourself.

Different women described their degree of involvement in an HIV community differently, for some the formal space of a support group was critical, while others were keen to maintain diversity in their connections and social worlds but also

valued an HIV-specific space. For Alice, a 68-year-old white British woman, HIV community was important but not sufficient:

I would not wish to define myself, by my HIV status, although it's a very important thing, an important part of my life, any more than I would wish to define myself by a mental health status, because I've had depression and anxiety but I would not wish to therefore spend my time focussing on that sector. Ditto HIV. Because there is so much more to life and I don't want to be confined. On the other hand, I have made some exceptional friends of people in the HIV community, because you are honest to other people living with HIV. You have a directness that you don't have with people that you meet.

Community could be found, accessed and integrated in different ways into the wider life of the individual. For Michelle, diagnosed 16 years ago and aged 50, her initial interaction with an HIV community was online, with people in the US and Australia.

Some women also described challenges in the HIV community. Yvette described an experience where her daughter was told about her HIV status by someone who attended the same support group as Yvette. Gossip and rumours were a problem for the HIV community, Yvette felt, because it was a tool to deflect attention from the speaker onto others. She also described finding support groups that were not well-structured and topic-focused to be challenging environments where political discussions and assumptions based on country of origin could dominate. This points to a challenge as experiences of HIV diversify. It is perhaps inevitable that different points of access and topics of discussion will emerge, but these may be less acceptable to some participants than others.

Cecilia also discussed complexities around disclosure in the context of an HIV community, for example where she had connections to friends or family of people attending support groups with her. Similarly, she described how meeting people in other settings could lead to difficulties if it was unclear whether it would be appropriate to speak to them or identify yourself in relation to HIV.

In their narratives, many women diagnosed long-term with HIV reflected on how the HIV community had changed over time. What emerged was a sense that changes had occurred, often with positive drivers, but leading to a fragmentation of the connections within the community. Drivers of this change included the

passage of time itself, changing priorities or circumstances, such as new jobs or children growing up, acceptance of HIV status, and the advent of effective HIV treatment. While women reflected positively on these changes in their narratives, there was also a sense of loss, of what the community had been and the positive role it played, that for many women was now reduced.

Cecilia described how community, and her connection to it, had changed over time. While she now had less regular contact with people living with HIV, it continued to play an important role in allowing her to talk about things she struggled to discuss with other people:

I have about two friends who live down the road from me, they walk in and we do have conversations, we're now ageing, we're diagnosed with mild arthritis, so people come and talk about that, they talk about the medication and what impact it will have as you're ageing, because we don't know what it could do with our hearts, we don't know what it could do with our metabolism. So it's all those things, around, you know, having people you can talk to. Because with my family I rarely talk about the medication and the side effects and the worries, but with my friends, we'll chat.

Cecilia contrasted the early 90s, where large groups would meet and her children were growing up within an HIV community, to a time now where people have moved on, and many of her concerns were those of any woman of her age, so the support and fellowship she sought out was not necessarily from others living with HIV. In her story, she shared more regret over this loss for her children than for herself:

I think it's important to them and I try and press it to them, you know, like recently one of my friends had, her daughter invited my daughter for a meal, and they used to meet at Positively UK, when they were children. And my daughter was like 'oh gosh should I really go?' And I'm like 'that's your community, your community maybe the children you went to school with but it's also the children you grew up with and it could be the children of your mother's friends, or your parent's, your father's friends, so make that link because when you grow up, when you need support, those are the people you will need to reach out to'. And she went for the dinner and really enjoyed it, really enjoyed it, so they do miss it.

Looking ahead, women often described community continuing to change, alongside their needs in relation to it. Cecilia described her hopes for reunions to

bring together people who had grown disconnected, while Alice hoped for the continued ability to seek community with diverse people. For those who placed their sense of community in formal support groups, the concerns were mostly about access and funding, with Leila describing her fear over the potential loss of funding for support groups and the negative impact that would have on her happiness and connection to other people.

A lack of services and support for women was highlighted by Patsy, who noted that as a white, trans woman, she could feel very excluded. She described often being the only woman at her HIV clinic and seeing posters for services and advice that did not speak to her experiences, and consequently feeling unsupported:

What you do is you go, as a woman you go to the clinic, you get your drugs, you tap out your bloods, you get your results and you come away again, back out into a world that is terribly harsh towards women and HIV. And I think that stigma, I think the stigma that women face, is so silent that it's just, it's kind of poundingly evident if you are a woman with HIV, but actually you wouldn't know that because, you know, it's very seldom kind of talked about.

This indicates the value and ongoing desire for HIV community, even as it changes over time. Women's stories were infused with the sense of a collective, of a community coming together to support and uplift each other, and to overcome challenges, from diagnosis itself, to health issues, to societal stigma. These were narratives of resistance, of accepting HIV while refusing stigma, fear and shame. Every woman described her feeling of being supported as consisting in also providing support, a mutual exchange in which community members contribute as well as receive, and in doing so create a shared identity and belonging. This resonates with the work of Emejulu and Bassel (2018) on the politics of becoming, described in the introduction of this thesis, where through care for others who share a status that is stigmatised, a collective political subjectivity is developed as a refusal of the dominant hierarchy. This is discussed in the final section of this chapter.

8.2.2 Talking about HIV – secrecy to openness

'Disclosure' is a frequently used term in relation to HIV, to describe sharing your HIV status with someone or some people. Advice is provided by healthcare and

support workers on how to prepare, what information to have to hand, when and how to 'disclose'. In the participatory analysis workshop, women debated the term itself, as some felt it carried negative and unhelpful connotations – you disclose a criminal record, but not diabetes, so why use the term for HIV? This indicates an evolving politics within the HIV community, as concepts and practices are debated and changed over time. The analysis workshop participants preferred the language of 'talking about' HIV. This also better captures the continuum of sharing and discussing HIV, which was evident in many narratives. While some had not shared their HIV status at all outside of clinics and support groups, others talked very openly about their HIV, even in national media. But even when this openness was evident, there were still limits on when and to whom HIV should be discussed, and challenges in considering how to do it and why.

Talking about HIV is not a single event, but an ongoing, mediated, complex process that requires thought and attention. Importantly, this continuum is an individual one. For some women, they had moved over time, from diagnosis to the present, from total secrecy to significant openness. Others continued to only talk about HIV in safe HIV-specific spaces like clinics and support groups. The passage of time was therefore inconsistently relevant in women's narratives of talking about HIV. It is also not a linear process. Some women described becoming less open over time, or changing how and where they discuss HIV depending on other factors, such as their children. The consequences of discussing HIV were primary in most women's consideration, both for themselves and for their families. As well as awareness of negative consequences, women also assessed the potential benefits of talking about HIV, sometimes choosing not to due to feeling there was no benefit in doing so.

Speaking openly about HIV, for Yvette, is about healing and acceptance of HIV, although speaking publicly had some negative consequences, particularly among other people living with HIV who were concerned about their own status being disclosed by association. For others, the idea of telling even family members about their HIV status is overwhelming, and they prefer to restrict the information to their medical team and support groups.

Even those women who were happy to speak about HIV did so with restrictions. Yvette described being happy to speak openly but not to discuss how she acquired HIV, as she feels this supports a culture of blame and obscures the fact that anyone can acquire HIV. Alice had a career background in public relations and communications and sought to bring these skills into her HIV advocacy. This led to media opportunities, in which like Yvette, she refused to discuss how she acquired HIV:

But I was absolutely not prepared to talk about how I became infected, because if I were to do so, I would be the victim, and that would denigrate the many people I know who, if you like, got HIV by accident, who were with someone they didn't know was positive, or the person themselves didn't know that they were positive.

Both Yvette and Alice acquired HIV through rape, and were reluctant to publicly discuss this due to fears that their stories could be used to perpetuate blame or distinctions between different women living with HIV based on how they acquired HIV. It is not unusual for women living with HIV to refuse to speak in public about how they acquired HIV. I know women who have ended interviews if this is asked, or participated only on the agreement that this question will not be asked. It is, in my experience, an accepted tenet of women's HIV advocacy that how HIV was acquired should not be shared. This suggests a community-imposed limit to openness about HIV, a restriction on what parts of a story can be shared which, though motivated by individual good intentions, nonetheless is a limitation.

Women also described the potential impact on their children as limiting openness. This again was not linear or straightforward. For Michelle, openness was a response to tragedy. She began to be open about living with HIV following the loss of her son to suicide. She described having previously been careful to hide printed information and limit who she talked about HIV with, but then following his death, feeling that being open and living without shame was important for her and her daughters:

But also that, that living in an environment where there's that sense of fear, and sense of shame, and sense of, you know, you can't be who you should be, and you can be proud no matter what's happened, and, you know, mistakes happen, and you do stupid things but it doesn't stop you from being a great person. So, that kind of, changed.

As she moved into openness about her status, the process of talking about HIV remained complex. She is open about her status on social media, so assumes friends who are connected with her online know, but she described having close friends who have never mentioned it. Similarly, her work colleagues are aware of her HIV status, but it has not been discussed. For Michelle, this is positive in that it demonstrates there is no stigma:

And I, I don't know whether it's, they don't wanna have a conversation about it, or they don't feel it's appropriate to have a conversation about it, or even because I'm not starting a conversation about it, you know. Maybe they're waiting for me to say something. Or maybe it's just not important. But it's a nice place to be, in that I am who I am, and it is what it is, and I don't appear to have lost any friendships or any business or any, anything as a result of it.

Discussing HIV with your family, and the impact of sharing your status publicly on your family, both dominated. For Yvette, moving to the UK enabled her to be open about her HIV status because she had no family here, whereas in South Africa, where her family are, the consequences for them could be damaging:

Here I don't care because I don't have family here. I don't have anybody to degrade, because if you've got HIV your family will be degraded, will be treated, 'oh, her mother's got HIV', things like that.

This had not led to open discussion within her family however, as she shared that she expected her daughter did know about her HIV, because “everybody knows”, but they had never discussed it. She recounted an incident where someone had sent her daughter a leaflet that included her photo, and when her daughter phoned to discuss it, she told her not to concern herself with what other people were saying, that *“I will have HIV when I tell you, at the moment I don't.”* This complexity, even incoherence in approach, reflects the sense of discussing HIV as an ongoing and unclear process, not a one-time event but constantly navigated and negotiated.

The consequences of revealing your HIV status, either expected or experienced, varied. Many women described their fear of stigma and discrimination. For Gladys, diagnosed for only four years, socialising with people outside her family and support group was very difficult as she felt unable to tell them her HIV status. For Leila, diagnosed for 11 years, migration prevented her from talking about HIV

to her adult son living in her country of origin. She felt she would only be able to do so if they were able to meet in person, and she had the support of an organisation which would advise her on what to do and support him directly. At the Food Chain workshop, one participant said her family only knew because her son had opened a medical letter sent to her, and she was uncomfortable now whenever it was discussed. Another participant summarised the predicament faced in deciding whether to talk about HIV:

Because you risk two things, let me say one thing, rejection or acceptance. You find that they can choose to reject you or accept you. So how would you know that they are going to accept you?

Often, decisions about whether to discuss HIV were made based on an assessment of the potential consequences. Adanna worried that her status would prevent her finding employment, so concealed her experience volunteering with HIV organisations from her CV. Sara kept her HIV status secret from her sister, though her parents knew and were supportive, as they all agreed that her sister might react negatively. This was maintained until her sister passed away, and for Sara was a necessary omission that protected their relationship.

Maintaining secrecy was a burden for many of the women that I spoke to, but one that was often deemed better than risking the alternative of stigmatising or discriminatory consequences. This decision was not always made independently. Michelle had been encouraged by her medical team to keep her status secret when she was diagnosed during pregnancy:

So I was told by the doctors and midwives and everyone not to tell anyone, and that's kind of, I understand why they do that, and they still do that now actually, because they see you as a pregnant woman as someone who's vulnerable and needs support from family, and if you reveal your status they think that the family's gonna disappear, and I can see that, and I had experience of that happening, with, you know, other women living with HIV and myself. But I think when you're, the, the seeds that are planted early on are very, very powerful... But they also, it was the way they kind of all colluded together to make it so that no one knew, so that none of my family knew, and, you know, things like, being, not being able to breastfeed, the stories that then my midwife, you know, they lied, basically, They lied. And I think that's an interesting, looking back on it,

how, they behaved and how that influenced how I then behaved, and what was acceptable, and what wasn't acceptable, yeah.

Patricia described a similar experience from support groups, where participants and their children were encouraged not to talk to or acknowledge each other if they met outside the groups, to protect confidentiality. In this way, the fear or expectation of stigma is passed on and maintained, and influences behaviours and decisions even where the individual involved had not personally experienced negative reactions. Indeed, many of the women who participated in this study described more prosaic consequences than the discrimination they had feared, though these too could be hard to manage. Alice was given the opportunity to appear on television for an interview about HIV, and described her fear at what consequences she might face, especially as she lived in a small town:

And the reaction of people getting in touch was always positive, because that's the only people that will get in touch with you isn't it? And, but, you, you had to talk to people, to make them realise you're alright. So it was like you had to counsel everyone, to, to show you were alright... There were some negatives but not that many. And those were from people you would expect, like people who were always in the pub, the particular pub I was talking about, now closed, but who were always there, because they're there to live vicariously, gossiping about what other people do, so there was that sort of thing, and they'd make snide remarks, or blank me or something, so, you know, just, ignore it or get away from it. But otherwise it was like the best thing I'd done because once you've done it, you've done. Once it's out, it's out. And so then doing anything else afterwards is easier and now it's like, easy, you know. And because it's no longer a sensitive issue, it's no longer something worrying to talk about, because that's who you are, that's who I am.

For Cecilia, worry about a similar need to inform shaped her choices on who to talk to about her HIV, as did worry about consequences for her children. She had positive reactions from her siblings, and valued the support she received from them. She told her children when they were teenagers, and because they were well-informed about HIV they took the news well. Outside of family, Cecilia felt that whether to discuss HIV was determined by the need or benefit to doing so, and the potential risks. She recounted walking as part of the London Lighthouse (an HIV support centre) delegation in Princess Diana's funeral procession, but turning down an opportunity more recently to appear on TV due to the risk of her children's friends discovering her HIV status. Within her friends, Cecilia described

a close group in which only one of the four friends knows about her HIV, as the friendship had been relatively recently rekindled, and:

I questioned, what, is there a need? Because I don't want them to start feeling sorry for me. Is there a need? And I keep thinking, whenever I have to disclose my diagnosis, I need to know why, whether there's a need.

For many women, their feelings about talking about HIV changed over time and depended on context. Patricia felt she had to tell her children once she was taking medication, as they would inevitably wonder about it. Their reaction was positive and supportive, as was the case for many women who discussed telling their children. However, as her children are growing up, Patricia is struggling with new questions over who to tell, as she wondered if she should tell their partners, and at what stage it was appropriate to do so.

Whether or not to talk about HIV for many women was contingent on consequences and benefits – who needs to know, and what is the purpose in telling them, was often the guiding question. These decisions are shaped by the expected level of knowledge about HIV the person has, as well as the potential impact on the relationship of either keeping the secret or discussing HIV. Some women described being very open earlier in their lives with HIV and now being more considered about the purpose of disclosing. Others talked about feeling that some people, family or friends, needed to know, while those less close did not. These questions were ongoing and changing, as dynamics and networks changed. Openness for some women was associated with accepting HIV. In some cases, having done this, women then moved on to less openness later in life, when the benefits were no longer so clear. Talking about HIV was multi-faceted, with decisions shaped by an assessment of the current benefits and risks of talking *in this way to this person or people*. For most women, there was not one continuum but many of them, and the choices made based on it changed all the time. These apparent contradictions are not likely to be resolved, as they simply reflect the complexity of life. They indicate the ongoing need for an HIV community where these challenges can be shared and understood.

8.2.3 Making a difference – stories as a source of change, research as a tool

Many women talked about wanting to make a difference for others. Often this was within the supportive framework they themselves had benefited from: women they met at support groups had shown them it was possible to live well with HIV and they wanted to do that for others. It was somewhat less frequently framed in typical advocacy terms of campaigning, public speaking and related activities, though that did feature for some women. Instead, the process of making a difference existed within the continuum of talking about HIV, from providing support to public speaking. A unifying thread between all the forms of advocacy, from individual to societal level, described by women in their interviews was the centrality of story. Stories, told and heard, are the core of shifting perceptions of HIV, both for those living with HIV and in wider society.

Research itself, as an opportunity to tell your story and to contribute to evidence to support calls for change, was framed by participants as a form of advocacy. In this way, I found that both I and the participants were constructing our roles as advocates and the research became a shared form of advocacy. Understanding the research process as advocacy included, for some participants, placing responsibility on me as the researcher to act on what they had shared. This ranged from encouraging me to share findings and try to ensure the 'right people' knew about the outcomes of my research, to more explicit encouragement from participants like Patsy to ensure my research made a difference.

Interpersonal advocacy, using your story and experiences to directly inform or influence another individual, featured heavily in women's narratives. Some women, such as this participant at the Food Chain workshop, talked about telling her story to inform professionals and others living with HIV:

...one thing that I have found positive is that we are living examples that HIV cannot define you, to a younger generation who are living with HIV if they saw us, if we went and gave them our testimony that always give their hearts, encourages them, it motivates them, that is one thing that I've found. Me as a positive speaker, going to do talks in universities, especially to the midwives who are training, I give talks, and you find the way, the faces of the people light up when they realise that you have lived with HIV for a very long time. Some people still live in that old time that HIV, when you get it you are dead the next moment.

Yvette felt strongly about speaking about prevention, especially PrEP (pre-exposure prophylaxis), because she felt that there was a lack of information and support available at the beginning of the epidemic. She described a sense of obligation to ensure that others were not negatively affected in the same way. Other priorities included, for Alice, the importance of addressing side effects, which she felt were significant and widespread but under-reported to clinicians, and for Michelle, the need for spaces for women where specific issues could be addressed, and to encourage the use of language that is non-stigmatising, such as 'transmitted' rather than 'infected'. Importantly, these all reflect current priorities: women defined side effects, inadequate prevention information and the need for women-only spaces as issues of the present. Indeed, for many women their narratives of advocacy and making a difference reflected changes in their own roles over time, but not in the issues they prioritised.

Political participation or advocacy were also important to many women, who often expressed different motivations as well as challenges. Yvette struggled with the technical language used and the expectations placed on community members to understand it. Alice, alternatively, was drawn in by recognising similar challenges affecting others:

I suppose, what propelled me into HIV activism was that I was useful. I was useful to, to people, because I was good with words, and I could, with no training of any sort or description, but because of what I'd done, and I've got a very good legal mind, I could support people, if you like, before I knew the word 'advocacy' and 'peer support', before those words were in my head, I was doing that, quite naturally. And have continued to do so, ever since.

Rebecca, a 64-year-old white British woman was diagnosed with HIV while in prison, 30 years ago. She was involved in both Positively Women and ICW, advocating for the rights of women living with HIV in the UK and internationally. She described her motivation to advocate for women and to be part of a global movement for women's rights as having been somewhat surprising as she had not previously identified with feminism, but her story reflects a different form of feminist advocacy rooted in care for others (Emejulu and Bassel 2018):

Well, it was very strange because I was never like one of those feminists, like burn your bras sort of, I never really thought about

it, because I mean, I was just, you know, I was using drugs, I never really thought about it when I was, never wore bras [laughs] do you know what I mean, it just didn't come up, with my lifestyle, and things. But, it was then very, I mean it was very weird, well not weird, but the fact that I got involved just with women, but it was because, purely because the issues were so different and, and you know, for instance as I said, I had, you know, symptoms, you don't really want to sit with gay men and talk about, or talk about relationships. So, so it was so different. And women with children, and having carers, and I could just see that the issues were so different and there weren't any services for them so I, I got involved in that way and I was very passionate, although I wasn't sort of like a passionate feminist before.

But advocacy was not just a way to make a difference, but also a tool to distract from the trauma and loss that defined the early stages of the epidemic:

So I think, it's, because you didn't have time to grieve or to deal with what we were dealing with, which was death on a daily basis for, for me it was like over a decade, it was like, I don't know, you just, to get through it, you just do it. And, you know, I channelled all of my stuff into, you know, activism and doing something about it.

The emotional or practical weight of advocating featured in Rebecca's story and in others. The sense that not enough has changed despite all the time that has passed also resonated. Yet women shared a desire to make a difference and to take part.

Participating in clinical trials or informing medical knowledge and practice in other ways was for some women an important way to make a difference. Violeta described her experience during a period of hospitalisation following a stroke:

So I have to say that when I was in the hospital, I was, because it, the [London hospital] is a teaching hospital, I had all the students, come to me, you know like, asking for my story, you know, and everything. But I was, I was happy, because it was for science, you know.

For Yvette, it was a simple choice:

I just do clinical trials, just to, to be counted on helping and doing things.

Asked to reflect on what she might change in her life, if she could go back, Patsy reflected on how her life experiences had led to her advocacy, as a trans woman living with HIV, a writer and activist:

If I could have been born with a womb that would have been nice, I'd change that. But, because I suppose if it, if the question is really, really about what would you go back and change if you could change anything, then you know I, to be born in the right body. But, would I be writing stuff now if I had been? You know, I have to say that, there does feel like there's some value in my life, the work I do. For more than me. So, it feels like my visibility matters, at this particular time in history. I'm not over-blowing my importance... but at the moment it's quite important to be me and be visible. And all, everything's that happened in my life, not having a womb, being diagnosed at the end of year one, I mean in a way there's a kind of poetic beauty to that. You know, which is uncomfortable, which is, which seems spiteful, but actually there's a quiet poetic beauty that enabled me to become good at advocacy.

8.2.4 Personal communities – HIV as bridge or barrier to partners, friends and family

In different ways, diagnosis with HIV opened up new connections and communities for all the women I spoke to. In many cases, those personal communities also contracted, as HIV led to the loss of some connections, or interrupted others. Some women described feeling unable to disclose their HIV status as a barrier to certain relationships, or a limitation on others. In this section, I explore the role of HIV as a bridge or barrier to partners, friends and family as well as to other communities (the subsequent section focuses on motherhood).

HIV was often described as being a barrier to intimate partnerships. For many women, sex and relationships felt impossible following their HIV diagnosis, due to concerns about how partners would react to their HIV status. This feeling had often increased as they grew older. In fact, sex was hardly mentioned at all in the workshops and interviews. In some interviews, I used the prompt 'what does intimacy mean to you?', and most women responded with ideas about closeness and emotional support. This is important not just because sex seemed not to feature in women's current lives or future plans, but also for understanding how and why HIV is a barrier to relationships. For most women, the concern was not transmission, so advances around 'undetectable means untransmittable' are not enough to address the barrier women are experiencing. Instead, concerns were around what a partner would think and how they would act if HIV was discussed.

Indeed, for both bisexual women interviewed, the possibility of a woman partner, with virtually no transmission risk, did not open up intimacy or partnerships.

Beyond HIV, menopause and ageing could also be a barrier to intimate partnerships. Women attending the AHPN workshop described the menopause as decreasing their interest in sex, and making it more difficult to find a relationship due to changes in mood.

For other women, intimate partnerships were not a priority given other difficult experiences. For Yvette, after experiences of rape, abuse, homelessness and immigration problems, having her immigration status settled, her own home and a circle of friends was enough and her hope was not for a sexual partner but a close friend she could trust:

I don't even think about it actually. No. It's gone. I think to me its trust. I don't trust. And I, it's not just about sex, I don't, my feelings as well. I don't like people playing with my feelings, so I just cut it off. I'm happy, my friends make me happy, I laugh, I do things. The only thing I don't do is sex, and I'm not missing it.

Women who had children sometimes described their focus having been on them, leaving little time or energy to seek a relationship with a partner. Angela, a 55-year-old with two teenage children, described feeling ready to start thinking about romantic relationships now her children were older and more independent.

For many women though, HIV itself was the challenge. For Tindo, this was further complicated by traumatic experiences including the death of her husband, being raped, through which she contracted HIV, and now living in a foreign country without friends or some of her family. In Tindo's narrative, her reliance on services, both clinical and third sector, is evident and applies even to her desire for a partner:

If I could I don't mind. I need a friend. But I'm a very, I'm so scared through what I've gone through, I haven't had a boyfriend since I came in this country, because of the trauma I have... But if it is through professional people who can introduce us, I would feel comfortable. But on my own to meet someone and think I can talk to this person and, I'm so scared. Very scared. But I would love to be with someone. I would love to be with someone who would be there for me if I'm ill. And I, the same as him as well, just to look after each other at our age. Because my kids,

they're grown-ups, they've got their life. They can't be there for me 24/7. So it's time for me to be with someone. A responsible person, because I know I'm a responsible woman as well. But through people who will be checking on us to see if everything is ok. Because this is a foreign country. It's different from back home where you are introduced to a family member where you know the family. That's why I'm so scared.

For Patricia, the barrier posed by HIV was not talking about HIV but the practical challenges of managing treatment, side effects, and pain:

I used to, once upon a time I had intimacy but, you know when your life is taken over by, you're taking medication, you're having side effects, you're, I think my priority now is just staying well, rather than looking for a relationship.

Similarly, for Patsy, it was HIV in combination with other factors, in her case being trans and over 50, that meant sex, relationships and intimacy felt inaccessible, as she felt society viewed women like her as unattractive and undesirable.

Some of the women participating did have relationships, which may have been affected by HIV in different ways but had not been prevented by it. Having a partner who was also living with HIV enabled Cecilia to maintain a strong marriage and was a source of support to both her and her husband, and she felt had protected her from challenges other women faced. Michelle described being “celibate” for four years after leaving her husband, and finding the prospect of starting a new relationship very difficult. She had though gone on to have partners, including a current boyfriend who was supportive, accepting of her HIV status and “he's tall and he's kind”.

Friendship was also important to some participants, though interestingly was not present in all narratives. For some women, friends were people, especially women, living with HIV, and non-familial social connections existed only within that space. For others, friends not living with or otherwise ‘involved with’ HIV were important. Angela talked about making a thoughtful effort to maintain friendships, for example with a colleague who was moving on from their shared place of work. Violeta talked about a number of close, valued friends not living with HIV, who had played a critical role in supporting her through HIV diagnosis, serious illness and bereavement.

For Gladys, diagnosis led to a break with her friends, as she felt she could not tell them about her HIV status. She had endured a period of illness where she was unable to socialise and felt unable to explain why. She prioritised having a small number of close friends she could be open with, rather than a larger number who might let you down. This seemed to represent a narrowing of her social world after diagnosis, though she was positive in describing her reasons for it. Similarly, Leila, after a negative experience when she told a family member she was living with about her HIV diagnosis, chose not to tell many people and to withdraw from her friends. For both Leila and Gladys, dealing with HIV, coping with treatment and adapting to diagnosis, were challenges that dominated their thinking and actions, to the extent that it was difficult, if not impossible, to maintain friendships without talking about it. Yet the prospect of telling friends about their HIV status was deemed too risky given the possibility of negative reactions, which effectively blocked the continuation of those friendships.

Sara mitigated this threat by maintaining two entirely distinct groups of friends, one of people living with HIV, through her support group, and another group that were unaware of her HIV status. This allowed her to continue relationships and social worlds, but was a source of worry:

And my friends, and this is where it's a little bit strange, my biggest fear, my big problem is my double life. I've got my non-HIV friends that don't know anything about it all, and then obviously my HIV friends... and the two worlds can never cross. I, I don't know why, I don't know why, in January when it was my birthday, my partner was trying to organise a surprise party for me, and from day one I always say 'I don't want a surprise party!' because the two groups can never meet. You know, because they're going to ask, it's the most common question, is 'how do you know [Sara]?' So that is my biggest fear, one of my biggest fears, that those two groups can never, ever cross.

Similar distinct friendship groups, and worries about the two meeting, were also shared by other women.

Family was also an important source of social connection and support. For some women, it provided a sense of grounding and identity, but for many women family connections were bound up in experiences of violence, loss and fragmentation. I opened life story interviews with the prompt 'where would you like to begin?', and for many women this started in childhood, talking about their family, where they

grew up and how they were raised. Within the limited space of this thesis it is difficult to do justice to these narratives. Cecilia's story and identity was bound up in family, from a happy childhood with parents and a large sibling group, where family, education and faith were prioritised, to the strength and values this gave her, and how it helped her to cope with the loss of her father when she was in her early twenties and her later HIV diagnosis. Angela too was grounded and supported by a big family, which helped her through the difficult experience of being part of the only black family growing up in a small English town, and through the premature deaths of her mother and her brother.

Women who had migrated to the UK had often left their family behind, and looked back to being surrounded by family as a time of greater support, as for Adanna, who after the breakdown of an abusive marriage in the UK, felt very alone with no family nearby. Violeta had spent many years caring for her mother in her home country in Europe, while living in the UK, which had been a significant emotional and financial burden for her and impacted on her own health.

Gladys had migrated to the UK to be with her siblings, after the death of both her parents and a subsequent struggle with depression and suicidal thoughts:

So when I came here I could, I can disclose anything to my sisters, anything, so it really makes me very, very happy, yeah. And them, they can disclose anything, anything they have they can tell me, but sometimes they can't disclose to anyone else. So I think that's, I'm very close to my family and it makes me very happy. They are more, I am more close with my family than the community outside there. I can disclose anything to my family, than people out there, regarding my status.

Beyond family and friends, some women talked about other communities they felt a sense of belonging to, including faith, LGBT and homeless communities. Each offered a sense of connection, belonging, understanding and support, though there were also tensions between belonging to different communities, and for some women HIV acted as a barrier to full belonging to other communities.

8.2.5 Being a mother, fulfilling expectations and making choices

Being a mother and the role of motherhood featured in all the interviews and workshops I held. Even for women without children, reflecting on their lives included consideration of why they had not had children. The identity of being a

mother, as well as the rewards and challenges that came with it, were significant for many. Challenges included integrating an HIV identity with the identity of motherhood, and migration as a practical barrier to fulfilling their expectations of the role of a mother. Some women described losing the opportunity to be a mother due to HIV, or other barriers including trans identity and health conditions. For some women, not being a mother was a choice and one which they were happy in. In recruiting to the life story interviews, I asked women at initial screening whether they were mothers and deliberately recruited to include a number who were not, in order to ensure these experiences were included.

Being diagnosed with HIV while pregnant or with young children imbued the early journey with HIV with added trauma. The need to survive to care for children shaped many women's initial responses to diagnosis, and centred the role of motherhood in their lives and survival. Cecilia and Patricia described their children as having been a motivation to survive. Patricia said:

But most worrying was, is my child also positive? And I had two other children, so I was, I was in a, a maze of worry and I didn't know what, what to focus my worry on, whether it's me, sometimes I would be like 'oh I'm going to die before I bring up my children', sometimes or maybe that 'my children are gonna die' because I didn't know, you know. It was until my baby was eighteen months, that's when they fully discharged her from check-ups and then when they definitely knew she wasn't, she didn't have HIV, which is great. However up to that point it was such a worry.

In this way, HIV shaped the experience of motherhood, and motherhood shaped the experience of HIV. Women described doing both identities differently in response to the other. This could be exacerbated by other experiences, such as migration, which were interlinked with HIV. Women who migrated to the UK from African countries described the loss of leaving children behind and the enforced separation, sometimes lasting many years, which resulted from delays in the immigration process. Tragically, some women's children had died during this period of separation and they spoke of their grief being magnified by being unable to attend the funeral. For example, one woman at the AHPN workshop said:

I did lose my son, it's a long time ago, but people say time is a healer, but I don't think so because it still remains, I haven't brought closure. I didn't, I couldn't go. And I miss my daughter,

I left when she was 9 and now she's 23, I haven't seen her.
Because of the immigration.

Leila too described in her interview the pain of being separated by the immigration process from her two sons, one of whom had died after she came to the UK.

Yvette first became pregnant through rape. She had three children in total, one of whom later died of HIV-related causes. She spoke of her daughter, with whom she was in regular contact, but did not mention her other surviving child. She talked about her fears for her daughter in South Africa, a place Yvette considers to be unsafe for women, and her concern for her granddaughter who has health problems. Being unable to see them or support them practically was a cause of great anguish. She described feeling guilt and questioned her role as a woman and a mother in choosing to remain in the UK, where she felt safe and had good medical care, rather than prioritising her role as mother and grandmother:

I haven't seen her for 17 years. I've got a granddaughter, I don't, I haven't seen her... It's terrible. She just share me the pictures. I feel like I'm a horrible person. I neglected my daughter. She was 14 when I left, and now she's 30 years old, and 'mummy come home, mummy come home'. It is just terrible. The only thing I can say is I can't come home, I don't want to come home. It's my choice. Nobody's stopping me, I'm not scared of coming, I just don't wanna come home. I don't have a life there. You know. How do you sleep at night? As a woman, how do you sleep at night?

The pain of separation from a child was shared by Gladys, who left her son behind when she moved to the UK to be with her sisters. Though sure she had made the right choice, the ongoing problems of unresolved immigration status meant the separation from her son had lasted far longer than she had anticipated, which she found very painful.

Not having children was a source of incredible grief for Adanna, who moved to the UK when she married but was treated abusively by her husband. Though aged 50 at the time of her interview, Adanna still hoped to be able to become a mother, describing efforts to pursue IVF which were laughed at by her GP. Not being a mother undermined her sense of self and her standing in her community, and she talked about considering adoption or other routes if a biological child was not possible, as she struggled to countenance a future without children.

Violeta and Patsy also mourned the lost opportunity of motherhood. Violeta had been unable to have children due firstly to HIV, then a secondary serious health issue, while as a trans woman Patsy had been unable to become pregnant. Violeta was pregnant when she was given her HIV diagnosis, and due to the lack of treatment available, termination was the only viable option. Later, while her peers with HIV went on to have negative children as treatment advanced, it remained impossible for her due to her other health problems. Her termination was a source of emotional pain:

So that is the phantom of my illness really, because I couldn't have children, and I see so many people with children now and everything, and now I'm in my 50s, my menopause, you know like, so the chances of having children now is like, less, and you know. And to me, you know, it's painful, to look back, and I understand the medical profession, I understand at the time, you know like, there was no meds so there was no way to bring down the risk of the child, to, you know for me to pass the HIV to the child like now, so I understand all that, but psychologically, you know, I, you know, it's painful.

For Patsy too, being unable to be a mother was painful.

... when I was in school I dreamt that I'd be a mother. And that's, that drove most of my young life, was dreaming that I'd be a mother. I genuinely didn't, I mean, to anyone that kind of disputes trans identities, I genuinely didn't believe that I couldn't be. It was only when it was made achingly clear to me that my biology and my physiology wouldn't support motherhood. I genuinely believed that I would be a mother. Not a father, so that was never on the cards, it was never about being a parent, it was about being a mother.

Sara also did not have children, having been diagnosed during pregnancy and encouraged to have a termination. Her views on having children were ambivalent, she had never planned to be a mother and described not regretting this, but the termination being difficult to come to terms with as she had not been able to make a free choice:

And it was one of those really weird things, that wherever you, wherever I went there was babies, it was so weird, because I'd never really wanted children, but as soon as you're told you can't have them, I want them, you know, it's, it's, it was quite strange, sort of how I felt about it all.

For women who had children, there were challenges beyond migration. The father of Angela's second child became controlling during her pregnancy and she chose to end the relationship. He reacted by making false allegations against her in order to try to win custody, and subjected her to a five year campaign of social service intervention and court cases before she eventually proved the claims were false. Parenting in the midst of this was incredibly difficult, but she still described her role as a mother as the thing in her life which had given her the greatest joy. This resonates with other women's stories, where despite the external challenges of HIV, stigma, the worry of not living to see your children grow up or the experience of violence or abuse, having and caring for children remained a joyous thing. Women who were mothers frequently described the experience in terms of pride and a sense of accomplishment, reflecting quite traditional, gendered notions of the role and value of motherhood, which HIV had sometimes disrupted.

8.2.6 Isolation and meaningful connections

In all the stories women told about their lives and experiences, in interviews and workshops, personal connections and communities mattered. And HIV mattered in these connections and communities. There was a shared sense that to have a fulfilling, meaningful connection, with friends, partners, family or community, honesty was important and that included being able to talk about HIV. For these women, HIV was a significant part of themselves, not just their health but their identities, and played a role in their daily lives, whether through health issues or side effects, or through the friends and communities that mattered to them. Having to keep this hidden from others represented a barrier to a meaningful connection to those others, whoever they were.

For some women, the need for secrecy about their HIV status, whether it emerged as a result of actual negative experiences or from the fear of them, led to feelings of isolation and disconnection. Loneliness as a result of this isolation was a particular struggle for women, especially those attending workshops where this issue was particularly discussed. This might reflect the greater dependence on support groups and formal support that these women, especially at the AHPN

and Food Chain workshops, described compared with many interview participants. For example, one participant at the AHPN workshop said:

So you are now lonely, you are now fearing death. You start feeling my heart, and oh maybe, maybe tonight I'm dying, because loneliness, most of the people here they live on their own, loneliness is, is sickening. For me its loneliness, I just get up, I don't feel I'm worth living. Loneliness is very bitter.

Tindo described her dependence on groups, in part resulting from her decision to isolate herself from previous friends and networks following her diagnosis as she was afraid to tell them her status:

It was difficult, you know, I was in denial. And up to now you know I'm still in isolation, you know, just thinking that, you know, how do people judge me? How do they see me now? Is this thing on my forehead and, you know, I can't find friends. I've, I don't answer calls, up to now I just change my line, I don't have, you know, contacts with people who I used to talk to. People from work, friends, my life has just changed completely.

This process of self-isolation resonated in the narratives of many women, who often had acted to prevent stigma by ending or avoiding relationships. The expectation of stigma was therefore sufficient to prevent meaningful connections, even if never or seldom actually experienced. There was little sense from women who shared these views about the potential for change in the future. They described depending on HIV support and clinical services, and fears about losing these lifelines. In terms of personal relationships, friendships or partners, they often described current barriers as static and therefore persisting.

Looking ahead to the future, many women feared increasing isolation as they grew older, either due to failing health or to the closure of services on which they depended. Patsy described her fears of a lack of support and provision meaning she faced a future of increasing isolation:

How isolating will it be, you know it really terrifies me, my future really terrifies me, because how isolating will it be for me to end up in, say for example, a care home, as an HIV positive woman, trans woman, maybe that will come into it, but when somebody has to give me my medication? How isolating will it be? Because it won't be that there's a, if there's nothing in place now, there's not a community in place now, it's certainly not going to be in place, by the time I get to a care home, kind of 30 years hence. And that's really worrying, that's really scary, that sense of kind

of isolation, and how that's only going to become more embedded.

Thinking about the future inspired similar worries for many women, who talked about fearing an old age defined by loneliness. There was often little sense that they could change these problems, by building or developing community and networks. This is an interesting contrast to other reflections on the value and sustaining role of community, perhaps indicating a sense of depleting agency with increasing age, as Patsy described.

8.3 Discussion

The overlapping between personal communities and wider social worlds is mediated by HIV, as are interpersonal relationships. In some cases this is an opening up, a bridge to new connections that are deeply valued, nourishing and significant. It can also represent a closing down, either the loss of relationships directly, or a barrier to meaningful connections posed by the keeping of a secret. The secret of HIV, where it is not discussed, does not seem to get smaller or easier, but instead to gain solidity and mass. Women who had not discussed their HIV status with their families, for example, felt unable to talk to them about other aspects of their lives. The process of talking about HIV is not captured by the act of disclosure, which implies a single event, but instead operates across a complex continuum, with what is discussed and how it is discussed changing over time, between and within relationships. It is a prosaic process, not necessarily planned, and not even necessarily known to have happened, as for example women who shared their status on social media so could assume people knew, but had never discussed it with them.

The HIV community is greatly valued as a space of understanding and support, and for some women, their most meaningful connections are within this community. Emotional and practical support, especially in the post-diagnosis period, is sought out and valued from other people living with HIV due to shared experiences and understanding. The HIV community is, though, perceived to have changed over time. As treatment has advanced, funds have dissipated and people have adapted to HIV as a long-term condition, the structure and closeness

of the community is perceived to have changed. Women depending on the HIV community now describe it in terms of formal structures, support groups and services, which are dependent on funding that is reducing and therefore unstable to rely on. This is a source of real and growing concern for many women.

For other women, these formal sources of support have been effectively closed off by a transition in their roles within it, from a seeker to a provider of support. Women who moved into professional or semi-professional roles within the HIV sector described this as rewarding, speaking to their desire to be involved and to make a difference. However, it could also make it more challenging to get support when this was needed. Whether women had moved into this sort of role seemed to interlink with factors including especially migration status. In this sample, women with unsettled immigration status tended to depend on support, while British women and women with settled migration tended to provide support.

The desire to make a difference also motivated participation in advocacy and research. Each woman who joined a workshop or an interview came with her own motivations for doing so, and all demonstrated an awareness of the recording, my role as a researcher and my aims for the study, as well as their own aims in taking part. Some talked about wanting to make it easier for other women like them, in the hope that the research would have positive outcomes in terms of knowledge or services. In some cases this was made explicit, as I was asked to ensure my research had an impact.

As described by Corinne Squire in her work with people living with HIV in South Africa, this also reflected an understanding of the researcher as a conduit or channel to an audience, to authority figures, and to change (Squire 2008). This also invites reflection on the extent to which what women chose to say, both what was told and how it was told, was mediated by their understanding of what they thought would interest me and what they expected me to care about or understand. In some cases participants would interrupt their narratives to check that they were on the right track and not deviating from what I was looking for. I always responded to that question encouraging them to continue, saying everything was relevant, with the hope that this would lead to the stories women wanted to tell coming through more than the story they thought I wanted to hear.

The role of motherhood was of interest following the stakeholder interviews and participatory analysis workshop, where it emerged as something that was potentially over-centred, excluding women who were not mothers. This came through in the interviews, as being or not being a mother dominated many women's narratives. So too did wanting to make a difference within their community for other women, understood as supporting or providing advice or an example to individual women or groups of women, rather than for wider social change. This focus on the personal and the immediate marked out narratives of community and participation, which were defined through individual connections and shared experiences.

None of the women I spoke to were telling their story for the first time. For some, their story had been told many times, in support groups, immigration interviews, clinical consultations, benefits assessments, media engagements and public events to address stigma. Others, like Cecilia, had told their story very rarely, and she described her hesitancy in taking part. She decided to take part because she wanted to share her story, and to have the opportunity to reflect on her life and experiences. That process of reflection was evident in the life story interviews, far more so than the workshops, where more typical narratives of stigma, support and overcoming dominated. In the interviews, women delved more deeply into their experiences, speaking of bereavements, violence, and loss as well as coping and thriving. In this way the story became a process, not an object, and was shared with a purpose that resonated with women's descriptions of being part of an HIV community – to make it easier for others than it had been for them.

8.4 Analysis

Receiving an HIV diagnosis disrupts women's identities and planned futures. As well as adversity, this offers positive possibilities, including joining an HIV community. In their narratives, women described finding meaningful connection and emotional, practical and psychological support in this community. In part, the meaning and value of this community was found in the opportunities it provided to help others, by sharing experiences, passing on knowledge, and collectively making change.

In their work exploring the experiences of women of colour advocating against austerity in the UK, Emejulu and Bassel (2018) describe how government austerity is destabilising and further marginalising for women of colour, but also “creates new possibilities for women becoming radical agents for social change” (Emejulu and Bassel 2018, p.109). Advocacy rooted in caring for and about others opens up new political subjectivities, a “politics of becoming” in which activism rests on personal connections (Emejulu and Bassel 2018, p.114):

... we find that care is the crucial social relationship that guides many women’s activism and is an important dynamic for building solidarity for collective action.

This ‘care’ includes but goes beyond empathy and concern, as both “re-valuing and re-validating the views and experiences” of women who are otherwise excluded, subject to intersecting discrimination and de-valued (Emejulu and Bassel 2018, p.114). Through caring for others, and for themselves, women who experience exclusion and dehumanisation claim their own agency and value and engage in a political process of activism in defining new ways of being and collective action based on solidarity.

This resonates with the stories women told of belonging as a radical act of rejecting social stigma and claiming shared identity and experiences through community, and through that, supporting other women and making wider change. Turning to my research questions, the findings presented in this chapter respond to two specifically:

- How is the concept of ‘community’ relevant? What constructions of ‘community’ can we discern in the experiences, accounts given and discourses employed by older women living with HIV?
- How have collectivities of older women living with HIV, and others, responded to growing older with HIV, for example, through peer support and activism? Does this suggest a ‘biomedical citizenship’ and how might this function? How does this counteract or mediate notions of ‘community’ for women living with HIV?

The concept of ‘community’ is relevant, and is defined through personal communities with HIV community at the centre, formed through shared identity and experiences. Women’s conceptions of ‘community’ differed, including

persisting and newly emerging connections and connections that changed over time. HIV community was important in many women's personal communities, and belonging to an HIV community, connections to other people living with HIV and peer support were understood as forms of activism. Even women who did describe participating in typical advocacy activities such as media engagement and public speaking, including Alice, Patsy and Yvette, described not just their motivations but the activities themselves as being for other people living with HIV.

Outside of funding of specific support services, no participant talked about political decisions, national policy, budget priorities or any of the macro systems or actors normally understood as relevant to advocacy. Instead, these women situated their advocacy within their own lives. By living well, telling their story and supporting others, they were rejecting the stigma society attached to them and in doing so, undermining its foundations. When who you are is stigmatised, being who you are is a radical act, and the personal is political. This implies a rejection of biomedical citizenship when understood as an individual, client-based model. Even where women outlined their dependence on clinical services, this was through the interpersonal connection to their consultant, and the value in support services rested primarily in providing connection and space for interaction with the community. The HIV identity women described was collective, found through community rather than individual citizenship. It included the biomedical, as some women talked about treatment, for example, but went far beyond this, and focused more on a social or shared identity. This perhaps reflects the incomplete process of biomedicalisation of HIV itself. As long as HIV is a social actor, so will HIV identity necessarily go beyond a biomedical model.

The role of the 'expert patient', specifically the value in acquiring scientific knowledge in order to exert influence in your own care, emerged in some women's accounts. Lack of information, and challenges such as treatment side effects, was a motivating factor in seeking to fulfil this role. Technoscientific advances such as viral load testing were not priorities in women's stories. Women talked about managing treatment and their lived experience of health (such as pain and side effects), but seldom used the language of undetectable. While HIV as an illness has biomedicalised and the shift towards a treatment cascade that prioritises achieving a state of undetectability dictates the policy landscape,

women's narratives of HIV over time do not seem to reflect the same shift. This contrasts with the findings of Papparini and Rhodes (2016), reported earlier in this thesis, who reviewed biomedical citizenship in the context of the treatment cascade and found that biosociality, new connections and community forged through HIV, are diminishing in the biomedical era. Many of the studies reviewed for that paper reported on low or middle income settings where treatment access is insecure, and where HIV prevalence is high. In the UK context, where few pre-diagnosis ties to friends and family are likely to be with other people living with HIV, and where treatment access is secure and universal, the shared experience of HIV does seem to be sufficient, for older women, to forge and maintain community and social connections.

Interestingly, Papparini and Rhodes (2016) define the shared experience of HIV stigma as being insufficient to form community bonds. In their narratives, women defined belonging to an HIV community as more than a response to stigma, but also as a shared identity and community of care. At diagnosis, women may seek HIV community due to fears of stigma, but they also seek the support and advice of those with shared experience, and find friendship, mutual support and ways of adopting and adapting an HIV subjectivity that refutes stigma and embraces shared identity. Women did not describe their experiences as patients or clients, or exhibit gratitude, as Squire (2013) found, instead they articulated their desire for better drugs, fewer side effects, reduced stigma and improved experiences for women living with HIV. This suggests an activist, collective form of citizenship.

In my review of participation in the context of HIV, presented in chapter three, I considered whether biomedicalisation had shifted the HIV experience to an individual, client-based biomedical citizenship, from earlier collective, community-based belonging. In their narratives, older women living with HIV suggest this is not the case. Instead, through caring for and about other women or people living with HIV, they adopt a shared identity and reject both stigma at the social level, and clientship at the clinic level.

Time since diagnosis did appear to impact women's sense of belonging to HIV community, in particular as those more recently diagnosed often described more reliance on HIV support groups and formal services, while longer-term diagnosed

women often described moving from accessing to providing support. However, this is an imperfect measure to use, as Sara, diagnosed for 28 years, continued to regularly attend and value a support group, while Alice, diagnosed for 8 years, sought to inform and educate others by becoming an 'expert patient'. Instead, the role and form of community women described as accessing and valuing was influenced by a broad range of factors, including other forms of capital such as immigration status, employment and economic position. Each women's account of community was in this way unique. One clear difference was the extent to which women had 'migrated' their HIV social connections into a wider personal community, outside the confines of formal structures. Barriers to this existed for different women to different extents. Sara worked hard to maintain an absolute boundary between her general and her HIV social networks, so continued to value the formal space of a support group. Others had integrated their personal communities more and so felt more comfortable continuing connections found in support groups outside those structures.

In the context of ongoing cuts to services and a push towards self-help and time-limited services, as Squire (2013) identified, this suggests interesting and important challenges for HIV support services to consider. Tindo could only imagine starting a relationship if she was introduced and supported by a professional, and Leila could only envisage telling her son her HIV status if both of them were supported by an HIV organisation to navigate the process. Both women identified with an HIV community and appreciated a mutual sense of support and belonging with other women living with HIV, yet for these important life experiences, formal, professional support seemed to be essential. This indicates the boundaries of what community is considered to be able to provide, which was different for different women. It also indicates important considerations around individual coping, where are explored in the next chapter.

9. MAIN FINDINGS: RESILIENCE – ASSETS AND STRATEGIES

This chapter is based on a more deductive analysis than the preceding two findings chapters. While women's voices and narratives are again presented first, in section 9.2, the analysis draws throughout on relevant literature and takes a more orthodox approach. This chapter returns to the salutogenesis concept of health, exploring 'sense of coherence' and 'resistance resources', as outlined in chapter 4.1.2. The analysis draws on themes from the interviews and workshops, and does not attempt to map this onto an existing assets framework as such. It does, however, draw on the theory of assets-based approaches reviewed in chapter four.

9.1 Introduction

In their life stories, women described tools and resources that support them to live, cope and adapt to HIV, in different ways. These included faith, strength, purpose and independence as well as the experience of having grown through difficulties. There were significant differences in participants' socio-economic status and resources, with immigration particularly key in determining women's experiences, due to poverty and the lack of agency associated with insecure immigration status. The extent to which participants felt or described a 'sense of coherence' was informed by their acceptance of their HIV status, perceived ability to plan for the future, capacity to manage health and health status, and sense of control over their own lives and choices.

9.2 Themes and findings

9.2.1 Sense of coherence: accepting HIV; control and planning for the future; managing your own health

In assets-based approaches, a 'sense of coherence' is defined as the extent to which an individual feels they can manage their life, their life is meaningful and they are equipped to face challenges (Hopkins and Rippon 2015). This emerged through women's narratives about accepting HIV and learning to cope, and feeling they had learned or grown through their experiences. In addition, finding

ways to take control of their health and lives, and feeling able to plan for the future were important to a sense of coherence.

In chapter seven, I presented challenges and difficulties that women had experienced including bereavement, gender-based violence and HIV diagnosis. The concept of 'survivor conflict' emerged through the participatory analysis process, as we reviewed life story data and discussed the complexity of survival and the conflicting emotions it brings. One woman at the participatory analysis workshop succinctly captured this:

I'm grateful, but maybe I'm lucky, but maybe I'm grateful, but maybe it would be a little bit better if I died and I didn't have to go through all of this shit.

While this concept particularly captures the experiences of those women diagnosed before effective treatment, it is also reflected in experiences of women diagnosed later in the epidemic. In their narratives, women described coming to terms with HIV, not overcoming it. The idea of triumphing over HIV did not shape the stories women told, nor did ideas about HIV 'bringing out the best' in people. Instead of a linear narrative from diagnosis to overcoming to thriving, women's stories suggest an ongoing, incomplete and inconsistent process of assets, strategies and support accruing and dissipating, and coping as a continuous activity. In the participatory analysis workshop, women described how support groups and services can encourage a "heroic" narrative of overcoming that fails to adequately account for this important complexity:

I find that sometimes they [heroic narratives] silence the nuances and difficulties, and it's almost like the, the success and the appreciation and the gratefulness lives alongside the, I don't know, it's very, it becomes 'and then we overcame.'

Participants also cautioned that in an interview situation, women may frame their story within this narrative arc as they replicate the support group story structure they are likely to be familiar with, and/or to avoid seeming like a failure or being judged to be such by the researcher. Recognising the interview encounter influences how women told their stories, in analysing these transcripts I was attentive to this warning. Interestingly, while women's stories often included difficulties in the past, they also included current challenges, and ongoing problems. Many women did describe moving from diagnosis to living well with

HIV and the assets that had helped them to do so with some success, but no story followed a simple path to triumphing over challenges. Accepting HIV, managing their own health, planning for the future and a sense of control all emerged as important elements of a sense of coherence, and all were incomplete and subject to both progress and regression.

Accepting HIV and learning to live with it was an important part of women's ability to cope with HIV. Some felt HIV was the thing they would most like to change in their lives – often these were women who felt unable to talk about HIV openly and relied on support groups to cope. Other women were more open about their HIV, and felt this was important, for example, Yvette described accepting her HIV status as “healing”. Similarly, Angela talked about HIV and other traumatic experiences of her mother and brother dying having threatened her sense of self:

So yes I've had a lot of experiences of, you know, feeling like, you know, you could have gone under but it's not happening. So, so, you know, HIV was just another one of those things that for a while seemed like it was threatening in that kind of way, but I don't actually engage with it in that way. I, I'm more accepting, I like to think of it that I accept my condition, I am always looking to see how better can I work with the fact that I have this virus, you know, to find that balance whereby, you know, I'm caring for myself, I'm actually enjoying my life.

She described initially fighting against HIV as she had other challenges in her life, but moving to a place of acceptance where she could adopt positive strategies such as yoga to enable her to live with instead of fighting against the virus. This also allowed her to embrace the “gifts” that HIV had brought to her life, including friends and colleagues, as well as her work supporting other women living with HIV. For Sara, HIV had also brought people into her life she would not otherwise have met, and so because of the value she placed in her HIV community, she was able to accept HIV and would not change it.

Violeta and I had met briefly before her interview, when I gave a talk to a women's group at an HIV support organisation that she attended. The talk included some group discussion, where other women described coping with HIV by turning to god or making themselves up to look good. For Violeta, this was superficial, she instead prioritised accepting and managing your life and your HIV for yourself:

So when you were there like giving the talk, I just didn't think that they were, like, serious about the whole thing. It was funny, you know, but, you know, god is not going to help you, you know. It's you going to help you, you know, and yeah you can get your bag and put your make-up and go out, but when you come back home you still have HIV and you still have AIDS and you're still 50 years old, you know.

For Leila acceptance was contested. By taking treatment, she felt she had accepted HIV, but she was not able to accept the stigma that came with it, so her social world was limited to support groups:

I'm a little bit, because still sometimes when it hits you, you will sit and start thinking, or cry, especially if you go through some stigma thing, it make you cry. So I think that as a strong person you will not cry, so because it reduces me to tears sometimes, I don't think if I'm a very strong person. I'm strong in a sense that yes, I've managed to accept it and getting along with it, even before the medication, I don't want to take it, so for me to accept it, for me to start the treatment, is a bit stronger. But not, up to now not 100 percent, cause sometimes if it hits you, you, 'oh', you are down, you know? It can be hard sometimes.

'Acceptance' was an incoherent aim for Leila, given that stigma was intimately bound up with and ultimately inseparable from HIV. She wanted to take treatment and manage her HIV, but was not able to adopt or accept a social identity marked by HIV as this meant accepting a stigmatised identity. Acceptance was bound up in what HIV was understood to be. For some women, HIV as a social issue was a gateway to community, opportunities and support. For others, like Leila, the social meaning of HIV was much more bound up in exclusion, discrimination and loss, and acceptance therefore carried very different implications.

Linked to acceptance was the notion of control, which was associated with being able to make and enact choices. For Yvette, the two were part of the same process. She accepted HIV as a way to take control over it, and used that as a springboard for reclaiming control over her life more generally, and recover from experiences of rape, abuse and violence as a child and young adult:

What gave me joy, is, I was not controlled by HIV. I didn't let HIV control me. I did things that I never thought I could, HIV actually gave me kick, because if I didn't have HIV I wouldn't be sitting here with you. I wouldn't think of coming here. That fear of being told that you're gonna die, that made me live... I think because all the, I want to say the word, all the bullshit happened to me

as a child, people doing whatever. Invading my body, and I thought, I felt like HIV did exactly that. Just invaded my body, and controlling my life, and I didn't want HIV to control me. And I will never let HIV control me, never. I'm going to control it. It's going to sit there and lie there. Take the medication.

Yvette's understanding of control involved rejecting the negative social connotations of HIV and reclaiming her body and narrative. This contrasts with Leila's sense of a lack of control over the meaning and implications of HIV. Both associated treatment with control and acceptance of HIV as a medical issue, but the social meanings of HIV and their responses to them differed.

Some women talked about their fear of losing control as they grew older, particularly if they developed dementia or similar health conditions, or came to require social care. In the AHPN group, women talked about their fear of residential care, not on the basis of stigma, but because they would lose control, describing being unable to go out or attend support groups, have visitors or cook for themselves. These fears were rooted in not having families available to advocate on their behalf, reflecting the views shared in the participatory literature review: that women without children or families to manage their care were worried about being at the mercy of a system they could not influence. This indicates the sense that many women shared of their ability to cope being subject to external forces outside their control. Often, there was a sense of these ungovernable forces growing in number and scale as women grew older, particularly if dementia or similar conditions came into play.

For Michelle and Cecilia, feeling in control meant being able to cope with challenges they could not control directly, and taking control where they could. This process of understanding what can be controlled and how to continue to manage your life and choices within those boundaries, was an important theme for many women. Taking HIV treatment and prioritising HIV care was a core part of that as it allowed the individual to take control over their HIV, for Gladys and Patricia this was vital to wellbeing. For Michelle, diagnosis helped her to re-prioritise and make choices she was happier with, describing gaining strength from this process.

Outside of HIV, the process of learning with age and experience was important to a number of women, who reflected on the milestones they had reached and

the lessons they had learned. Shifting priorities reflected changing views as women grew older. For Cecilia, this meant working less and saying no more often, while for Alice, this involved prioritising her daughter. Importantly, when women reflected on how in control they felt over their lives, they considered both choices and priorities, as well as uncontrollable events like HIV diagnosis. Many women described feeling like they would do things differently if they could go back, and enacting some of those changes in the present, leading to a greater sense of control. Often the process of ageing was associated with feeling more in control, as women talked about learning from past experiences and choices. This is in contrast to future fears about losing control as women grew older, and suggests that ageing itself is not associated with a linear decline in how in control women felt themselves to be. Instead it is more of a bell curve, with steady increase as experience and learning is accrued, moving into steady decline as greater age impacts on cognitive ability and on social freedom (for example, being compelled to comply with the rules of a care home).

The expectation of future loss of control evident in many women's stories also indicates some negativity in looking ahead to the future. This chimes with the reference made in the introduction to this thesis to the future forecasting approach adopted in many HIV and ageing studies, and the risk this introduces of an overly negative outlook informed by worry more than reality. It is likely that many people, anticipating their own old age, would fear dementia, care homes and a loss of control. The extent to which this is informed by HIV varied between different women, as some talked specifically about fears around HIV stigma or struggles to adhere to treatment, but often the concerns were not HIV-specific.

In looking ahead to their futures, the degree to which life felt manageable and within their control was evident in the ability women demonstrated to look ahead to making choices. For women with unresolved immigration status, the future was very uncertain, and they tended to focus more on managing their HIV and awaiting an immigration decision with as much strength and patience as possible. Women not living under this uncertainty talked in more detail about future plans. Ambitions varied, from Angela feeling more able to prioritise seeking an intimate partner now her children were growing up, to Cecilia's hopes to be able to pay off her mortgage and retire from work. Financial worries were a dominant theme for

many women, Cecilia reflected that her hopes were conflicted as she did not know if she could afford the future she hoped for:

So then there's that niggling thing at the back of my mind, because when we were all diagnosed we all thought, you know, you're told you're not going to survive, so why have a pension? Even if it's a stakeholder's pension, why create one? And even working for [HIV support organisation] or [HIV support organisation], we never had pension funds, there was no, you know, yeah, so, we are in a situation where I think the only time I had that pension was in the [public sector]. But then you're, you feel there's no need for all this, so you then have to start thinking, OK, how will I survive?

Tindo felt unable to plan or even really imagine her future, as her feelings of isolation and lack of purpose led her to think there was little to hope for, especially due to pain:

Because right now I just think I'm waiting for the day to die. I just have to listen to the pain, complaining about the pain, talking to the pain, until it is in the evening, and then that's it. Until when? I'm tired. I'm tired.

Her interview was the most difficult to do, transcribe and analyse, because more than any of the other women, she shared significant sadness. She had recently engaged with a number of support services, and was seeing a psychologist, and talked about having some hope that these things might help. Her story demonstrates the potential crushing impact of an HIV diagnosis on sense of self, hopes and a sense of coherence, especially perhaps when HIV acquisition is linked to violence. She had been diagnosed for 10 years, so after the advent of effective medication and after HIV diagnosis was considered to be terminal. However, the impact on her life was very similar to that described by women diagnosed in the earliest days of the epidemic, demonstrating that scientific advances alone are not enough to shift the meaning or experience of HIV.

Adanna described great ambitions for her future, including further education, getting a job, and a desire to find a partner and to have children. All these things were contingent on moving beyond the consequences of the breakdown of her marriage. She spoke with determination and optimism about a future that felt just outside her grasp, but she was confident would come within reach. For her, the future was about reaching the things she had not yet been able to, not the steady

decline of ageing. To some extent, the future women imagined was informed by how far they had come and how much they were worried about losing. Women like Adanna felt they had more to achieve, while others like Cecilia who felt more settled in their lives, tended to worry more about what they might lose.

9.2.2 Resistance resources: values; strength; learning from difficult experiences

Resistance resources are the tools or circumstances individuals have that support their resilience. As defined by Hopkins and Rippon (2015) these include coping strategies, beliefs, social support and wealth. Socio-economic status and resources are considered in the next section, while in this section I focus on the dominant resources women defined as helping them to live well, including values, strength and learning from difficult experiences.

Values were bound up in community, belonging and faith, for many women. Knowing what mattered to you and holding true to those values and to yourself defined many women's sense of what was important and how they maintained their inner strength. For Patsy, values were central to her identity and wellbeing. These included a commitment to freedom, open spaces and presence, as well as finding joy in words, as a reader and a writer. Honour, consistency and kindness were the values she prized most in herself and in others. She sought to embody these values in her work as an advocate and writer, and drew on them for strength and to live well in the face of challenges.

A sense of purpose helped Patricia to withstand life's challenges and to continue to live well despite problems with chronic pain:

I think my values in life is, you know, to, to be, to feel you have a purpose, which it can be a challenging one because then if you feel you don't have a purpose then what next? And then the other one is, I, I believe in, you know, getting up, doing it, if others can so can you, and just, you know, finding a way. Rather than feeling defeated and feeling 'oh there's nothing else' and I think, I, I get it from my grandmother, because she always used to tell me, even when I'm lazy or when I'm feeling tired, she would, she would always add me an extra chore and say 'you know, work fears to be touched so if you touch this one it will just go.' So I always believe, even when I'm not well, I always believe when I get up, if I can do this, if I can clear my sink, I just believe in making order and feeling like, on top of something,

and then I feel, even if I'm in pain, at least my house is clean, at least I have my clean bed.

Inner strength was also a resource shared by many women in their life story interviews, where the prompt questions I sometimes used invited women to reflect on whether they felt they had this and how they maintained it. Often women hesitated to describe themselves as strong, but reflected that it had taken strength to come through the challenges they had faced and to be living well and coping with HIV and older age. As the listener to their stories, all the women I interviewed seemed strong to me, as they shared experiences that necessitated huge resources of inner strength to survive. Violeta differed somewhat from other participants, in that she looked at the accumulation of difficult, traumatic experiences of her life and was proud of the strength they evidenced in her:

All these things that happened, sometimes I do amuse myself, how strong I am, you know, like, and when I tell people about my life, you know, they go like 'really, really?' It feels that I'm not talking about me, it feels I'm talking about a film that I saw, something, you know. It's very strange, but, but then when I come down to reality of thinking, my god, I'm very brave, I'm very strong. So I'm not surprised I'm still here. You know? And I'm very, very headstrong when I want something. So even when they were telling me that I was dying, I was going no I'm not dying, I'm not dying, I'm not dying. And I didn't.

That sense of growing strength through surviving emerged in other interviews as well, in relation both to HIV and other traumatic or difficult life experiences. Yvette described her strength as emerging through having to teach herself to counteract fear and lack of support and safety. Angela credited her strength, and specifically her ability to manage her HIV diagnosis, to early experiences of trauma and the accumulated strength of survival:

And I, just thankful that I come from a background where, one, I'd already experienced quite heavy trauma, I'd already lost my mum at an early age, so, there was some familiarity with, that your world can be turned upside down, it's really bad, but somehow you will come through. And I'd already lost my brother, in a traumatic, again another, highly, highly traumatic, he committed suicide, so, you know, that probably still is the hardest thing I've ever had to deal with. So having already been through those heavy experiences, I had an understanding, somewhere deep within me, that however bad this was, it wasn't necessarily the worse thing.

Having interests, passions and a sense of purpose helped many women to feel strong and resilient and represented important resistance resources. These ranged from advocacy and supporting others in the HIV sector, to hobbies, dance, yoga, and commitment to work, career development and education.

9.2.3 Socio-economic status: choices, agency, and migration

The extent to which women felt in control of their lives, able to make and act on decisions and to withstand challenges was necessarily influenced by socio-economic status. Quite simply, if women lacked the financial resources for basic survival, everything was curtailed. This was particularly evident in women's experiences of the immigration system, especially for those who were or had been subject to the enforced destitution of having no recourse to public funds, as a result of a denied application or over-stayed visa. For these women, homelessness, hunger and dependence on charity defined their experiences and undermined their choices and agency.

At the Food Chain workshop, women talked about depending on that organisation for food, and dealing with inappropriate or inadequate housing and being prevented from studying or working due to unsettled immigration status. Yvette was homeless for a prolonged period when she arrived in the UK, before finding the support to make a formal application for immigration status to the Home Office. During this time, she was subject to abusive behaviour by people who allowed her to live with them in exchange for domestic work, which was unpaid and unregulated:

It was on and off, people would say come and look after my child, and then when they start locking me in the house, then I run away again. They don't want me to leave the house, in case I, or they will take my phone, or they will take something that's valuable for me and hide it so I don't run away. So people, people abuse you when you don't have, and some people I didn't tell them the truth, and, but eventually they do know 'this one is lying, she doesn't have papers to work here', because they will start asking you for your bank accounts and your, NI, national insurance number. You know what I mean? And start telling you, 'oh, I have to pay the bills, the rent' and because you're new in the country, you don't know what's going on, and then they don't pay you, you just work like a slave.

Even for those not affected by immigration, money and financial stability could be a problem. Alice had lost her career and independence following her diagnosis and relied on social housing and benefits. She described the challenges of this experience but also how she had adapted, and learned to live within her new means and with limited mobility:

Anyway, but now you see, now because now I really don't have anything. I have a social housing flat, I don't have money, I have a pension, I don't have a source of income, I'm on a [patient involvement committee] so I get a hundred and fifty quid a day, it works out as about a thousand pounds a year with the number of meetings there are... But, so, that was digressing somewhat but I don't have money, I use charity shops really well, I can, food wise, I can really exist incredibly cheaply, I use virtually everything.

Agency, as well as money, was important. To be able to live independently, have security, work or be in education, were primary goals for women struggling with socio-economic challenges. Being prevented from taking control of this aspect of life was deeply upsetting for participants like Gladys:

Currently, according to, to my life here now, currently, according to my status in this country, since I'm not working, I feel really, I don't know, I just feel like I need to do something, you know, every day I wake up and I go somewhere, I do something, like other people. And I want to contribute to this country, like getting work, doing so many things you'll love to do. And when I came in this country, I went to college... and I studied social care with our elderly people, and I did that course for one year and I qualified with NVQ 1... so even today I still have my certificates and, when I look at my certificates and I see I'm qualified, and I can't work. So it, I really feel so bad, because there's nothing I can do.

The assets-based approach recognises the resources and abilities people bring to their lives and that influence their health and wellbeing, but must also account for the external factors that prevent people from realising their assets. In this study, poverty and immigration were the most significant barriers to accessing and benefiting from assets, and realising the benefits they could otherwise bring.

9.3 Discussion

I had planned to include the ‘head, hands and heart’ asset-mapping activity, described in chapter four, in the participatory workshops. However, this did not work out in practice, because in the context of the workshop dynamics the activity felt inappropriate. The women taking part were keen to share their experiences around the value and need for services and the threat posed by funding cuts, with each other but also with me as a researcher-advocate. In this context, prompts around how women coped and adapted independently were responded to with a different focus, representing the political motives behind women’s participation. When services are threatened, going into those spaces and asking women how they can cope without them risks supporting the shift from the state to the individual that has been associated with assets-based approaches (Friedli 2013). In individual interviews, it was more appropriate to ask women how they coped, maintained their strength and navigated difficulties, and these strategies, including holding on to values, learning with experience, and accepting HIV, are vital assets to understand in the context of healthy ageing with HIV.

Running through these women’s stories was a central theme of community and belonging, that is important to consider in relation to the knowledge, skills and passions that allow living and ageing well with HIV. Belonging to a community of women living with HIV was vital to improve knowledge about coping with HIV, gain the skills to manage HIV, side effects and other health conditions, and social challenges, and for many women provided motivation in supporting others. The assets presented in this chapter must therefore be read in conjunction with chapter eight, as community emerged as a vital asset to support ageing well with HIV.

9.4 Analysis

The findings presented in this chapter respond to two of my research questions:

- How are these experiences [of ageing with HIV] mediated by gender, sexuality, ethnicity, migration status and experiences, or other factors?

- What assets do women hold and use to mediate their experiences, and in what ways are they used? Is the notion(s) of 'community' amongst these assets?

Women's sense of coherence, socio-economic position and resistance resources are influenced by a range of factors. Primarily, immigration status emerged as the key driver of the extent to which women had access to these assets. Women who were navigating ageing with HIV while also dealing with immigration processes were more likely to struggle for adequate food, housing and stability, and consequently to feel less control over their life and less able to pursue values and interests. This is linked to ethnicity by virtue of migration patterns, though ethnicity alone does not drive the issues. Gender also played a role, as many of the experiences that led to poor socio-economic status, past trauma and undermined strength and stability were linked to experiences of gender-based violence or abuse. Sexuality did not emerge as an influence over the assets women had and had access to, though it did interlink with experiences of violence and instability for Yvette.

The assets that emerged in women's narratives included the strength that comes from having survived experiences of trauma or difficulty, having interests including work and volunteering, hobbies (creative and physical), strength, having and maintaining values, accepting HIV, feeling in control, the ability to make and act on choices, managing one's own health, planning for the future and learning with age and experience. While not presented in this chapter, community and a sense of belonging and social, emotional and practical support emerged as the most significant asset which, as detailed in chapter eight, women credited with allowing them to process their HIV diagnosis and learn to live well with HIV, as well as providing wider support in their lives. This community is a vital asset for women ageing well with HIV.

In chapter two, I referred to a study conducted by Psaros, Barinas et al. (2015) which developed a typology of strategies to support living successfully with HIV over time (shown at Figure 3). The model includes barriers and facilitators to successfully coping with HIV over time, divided into cognitive and behavioural processes. Mapping the data from life story interviews and workshops onto this model, helps to illuminate key assets supporting women to age well with HIV.

Cognitive processes facilitating successful coping, defined by Psaros, Barinas et al. (2015, p.126) are: “dispelling internalised stigma, acceptance of HIV diagnosis, appreciation of perspective gained from HIV, confidence in illness management”. The process of accepting HIV, and building confidence and ability to manage health, emerged strongly in women’s stories. Moving beyond stigma and developing positive self-image also featured in some women’s narratives. The notion of learning and gaining perspective from HIV (and other challenging experiences) was also important to some women. These cognitive facilitators were all important in women’s ability to adapt to and cope with HIV.

The behavioural processes that facilitate successful coping, defined by Psaros, Barinas et al. (2015 p.126), also have resonance with my findings. These are: “caring for mind and body, changing/eliminating negative relationships and environments, engaging in meaningful activities” (Psaros, Barinas et al. 2015). ‘Caring for mind and body’ was described in interviews and workshops, including HIV treatment, exercising, eating well, managing other health conditions and caring for mental wellbeing. ‘Changing/eliminating negative relationships and environments’ was important in some women’s stories, including Rebecca and Patsy who had moved on from drug use, and Angela and Michelle who had left abusive and controlling relationships. For other women, the process of adapting to HIV and successfully coping had included being brought into negative or challenging environments, and some women were still struggling within them. This suggests an important area to focus support and resources, as coping well with HIV is linked to broader safety and ability to manage positive relationships.

The final facilitative behavioural process is engaging in meaningful activities, which Psaros, Barinas et al. (2015) define as including HIV-related advocacy and causes. In my analysis, a sense of purpose, belonging to an HIV community and supporting other women living with HIV all featured strongly as positive experiences and assets that supported women to cope with ageing with HIV. This sense of purpose and of belonging was described by many as vital to both initial adaptation to HIV diagnosis, and finding meaning and support to successfully age with HIV.

With respect to barriers to successful ageing with HIV, the typology developed by Psaros, Barinas et al. (2015) differs from the themes generated in my research, especially in behavioural processes. Their model includes two behavioural barriers, “ongoing substance use, non-adherence to treatment and/or HIV care” (Psaros, Barinas et al. 2015). Neither of these behaviours were described by women taking part in this study. This does not necessarily indicate that no participant was engaged in these behavioural processes, but based on the stories women shared, adhering to treatment and HIV care were prioritised and valued as important to maintaining health and wellbeing. Though many women described struggling with treatment and side effects, the value in taking treatment was also recognised.

The cognitive barriers Psaros, Barinas et al. (2015) identified were: “inability to tolerate uncertainty to disease course, perceived stigma, perceived lack of support, active psychiatric illness.” All these barriers were present for some women living with HIV in this study, and those who described a greater sense of struggle and inability to cope often described these issues. However, these women were also likely to describe experiences such as discrimination, challenges with side effects, poverty, uncertain immigration status and limited social support. A major limitation in this model is therefore its failure to account for material factors.

In taking an assets-based approach, I sought to understand the skills, knowledge and passions enabling women to age well with HIV, while also acknowledging the challenges outside their control that limited this ability. The model developed by Psaros, Barinas et al. (2015) accounts for behavioural and cognitive processes, both critical to understand, but external factors such as socio-economic realities and the behaviour or actions of others are also significant and should be accounted for. Beyond the ability of each woman living with HIV to cope, is the reality of what she has to cope with, and that burden is unequal and inequitable. In understanding the experiences of women ageing with HIV, it is vital to recognise the differences in these experiences driven by social and structural inequities and differing capital. This was widely recognised by the women taking part in this study themselves, who often referred to challenges experienced by other women living with HIV and situated their own experiences

and ability to cope in relation to others, indicating the advocacy and belonging through care for others I explored in chapter eight.

The formal spaces of HIV community, particularly support groups, were also significant assets enabling women to cope successfully with HIV. Accepting and adapting to HIV diagnosis and building social, emotional and psychological coping was often associated with the support provided by other women living with HIV in groups, often accompanied by support from actors including HIV consultants and peer support workers. Collective responses to HIV are missing from the model defined by Psaros, Barinas et al. (2015), which instead focuses on individual, atomised coping and experiences. By neglecting the material, as well as the collective and shared, in favour of individualistic approaches, the model is limited and reflects a narrow neoliberal account.

The value of collective responses is reflected in the work of Watkins-Hayes, Pittman-Gay et al. (2012), who defined ‘framing institutions’ such as HIV support organisations and ‘framing agents’ including clinicians and advice workers, as critical to supporting women diagnosed with HIV to adapt successfully and live well. Drawing on research conducted with African American women in Chicago, they define coping with HIV as depending on the individual, the resources and social support they have available, and framing institutions and agents who influence how HIV is understood and accommodated (Watkins-Hayes, Pittman-Gay et al. 2012). Framing institutions include non-profit organisations (support groups, legal and housing support services, advocacy groups), government institutions and medical providers. The authors sought to understand the role these institutions play in accepting and adapting to HIV over time (Watkins-Hayes, Pittman-Gay et al. 2012):

Framing institutions generate language, adaptive skills, and practical knowledge that shape how individuals interpret a new life condition and whether they ultimately see it as a platform for growth. They operate as intermediaries between micro-level perceptions and actions and macro-structural forces and systems, positioned between one’s personal response to a new circumstance and the larger set of privileges and disadvantages that she experiences due to her social location.

Within these institutions, actors termed ‘framing agents’ provide support, language, resources, and conceptual frameworks to adapt and move beyond

diagnosis to living well with HIV. Watkins-Hayes, Pittman-Gay et al. (2012) describe a process of moving from expectations of 'dying from' HIV to eventually 'living with' HIV as women developed new conceptual frameworks allowing for this eventuality. Framing agents can support or impede this process, by providing insights or reinforcing stigma and negative expectations. Noting that personal networks are unlikely to be able to offer the level of informed support women described needing and benefiting from, the authors conclude that HIV support organisations are likely to continue to be important and therefore should be resourced.

Comparing the findings of Watkins-Hayes, Pittman-Gay et al. (2012) with my own findings, there are clear parallels. Support at time of diagnosis and afterwards influences how women understand and adapt to HIV. In many women's stories, there were framing institutions and framing agents who played a positive role in this process, including clinics and peer support groups in particular. There were also examples of negative influences from framing agents, such as the clinical staff who encouraged Michelle to keep her diagnosis during pregnancy secret from friends and family. There are two significant differences between my study and that of Watkins-Hayes, Pittman-Gay et al. (2012). Firstly, in their study, important framing institutions included Alcoholics Anonymous, drug rehabilitation services and similar drug and alcohol interventions, which were not described in my study (although some participants did describe a history of drug use).

Secondly, and more significantly, their analysis focuses on institutions including HIV support organisations and peer support providers, but the agents within these are staff rather than other women living with HIV. Watkins-Hayes, Pittman-Gay et al. (2012) do refer to some women living with HIV participating in their study moving into or being 'given' roles in framing institutions, as peer support workers, but there is no accounting for the communitarian role of other women living with HIV as framing agents or of a community of women living with HIV as its own framing institution. Comparing the stories women living with HIV shared in my study with the analysis presented by Watkins-Hayes, Pittman-Gay et al. (2012) there is a clear divergence, as participants in this study focused on other women living with HIV and rarely name staff or professionals. When women described

the value of and role played by support groups or HIV organisations, they focused predominantly on the social and emotional support provided by their peers.

Some women described specific services provided by HIV support organisations, such as shared meals at the Food Chain or the Joyful Noise choir led by Naz. However, in describing how they lived well with HIV, women focused on the support of other women living with HIV much more than on professionally provided services. However, it is also significant that this community and mutual support was often provided through professionally provided services. Rather than an individual relationship between client and service, the value lay in how services facilitate collective experience. The structures of a regular support group, a shared meal, or social activity were necessary to sustain and to access the social network of a community of women living with HIV for many. Therefore a similar conclusion regarding the continued need for, and necessity of sustained investment in, HIV support organisations can still be drawn.

10. Conclusions

In March 2019, as I was finalising this thesis, I travelled to New York for work, and took the opportunity to visit the LGBT Community Centre for an exhibition, titled 'Metanoia', a Greek term meaning the possibility of transformation after experiences of trauma or difficulty. Using archival materials, the exhibition explored community-based responses to the HIV epidemic, focusing on women of colour. Posters, magazines, leaflets and protest chants from the early days of the epidemic highlighted women being excluded and ignored, from the definition of AIDS itself to their support needs and recognition that HIV affected women too. "Women don't have AIDS they just die from it." "We demand women-specific clinical trials." "Women with AIDS can't wait 'til later, we're not your fucking incubators."

Through this research I have read many articles and studies on ageing and HIV. Virtually all start with the same few sentences, reconfigured only slightly, noting how HIV has been transformed into a long-term condition, life expectancy has increased, that ageing is now not just possible but likely. There has been a transformation, yet there has also been little change. For women taking part in this study, there remains a sense that women are expected to wait until later, excluded and ignored in HIV discourses despite their organising and advocacy.

I did not start working on HIV with a focus on women and gender, but as my experience and knowledge grew I became more informed and more passionate about addressing this exclusion. Similarly, my initial proposal for this PhD research did not focus on women, but suggested a comparative study with other groups. It was later, through looking at the evidence base and as the paucity of research on women and ageing became clear, that I chose to focus on women.

While women's invisibility within the HIV discourse has not transformed, there has been change in the experience of living with HIV. Women's stories, shared with me through this research, indicate the potential for individual transformation that emerges from a community of women living with HIV. This belonging, and the care for others that underpins it, also has the potential for wider change, as evidenced by the Metanoia exhibition. Women may have been invisible, but they were never silent.

10.1 Review of findings

My aim in this research was to explore women's experiences of ageing with HIV in London, using a feminist and assets-based approach and participatory methods to generate new evidence on these experiences. Innovative methods including body mapping, participatory literature review and participatory data analysis, alongside narrative approaches in life story interviews and workshops, also offer an original contribution to knowledge.

An empirical literature review provided the foundation. A narrative review of clinical literature on ageing and HIV demonstrated the breadth of health issues intersecting with HIV and impacting on the health of women ageing with HIV. A systematically approached review of social science literature on ageing, HIV and woman demonstrated limited evidence, especially in the UK context, and a need for more research exploring and disaggregating women's experiences. This review generated nine linked themes: social networks and relationships: intimate partners, family and friends; mental health, wellbeing and coping; care and social support; loneliness and isolation; stigma and discrimination; health needs and co-morbidities; socio-economic and practical issues; disclosure; and, ageism.

These themes indicate the challenges that women can face as they age with HIV, but also emerge from a deficit-focused research paradigm that predominated in the studies identified through the review, and under-accounts for assets, coping and positive aspects. This was an important finding of the participatory literature review I undertook to supplement the review, and involve older women living with HIV in the epistemic process. As well as a contribution to methodological innovation, this represented an expansion of the research findings to provide better insight into women's experiences. The participatory analysis indicated issues missing from the literature to include in later phases of data collection, in particular the role of HIV and non-HIV related social networks, the experiences of women who are not mothers and positive aspects of ageing with HIV.

The empirical literature review was complemented by theoretical and methodological literature reviews. The former reviewed literature on community and participation, broadly and in the context of HIV. This informed the theoretical

framework adopted and research questions explored in this study. The methodological review included literature on feminist and gender-based approaches, assets-based approaches, reflexivity and participatory methods, informing the study design and methods used.

In chapter five, I presented a review of policy on HIV and ageing, and findings from ten interviews with key stakeholders. Policy issues included the fragmentation of commissioning and reduction in services following the Health and Social Care Act 2013, and the implementation of government austerity. Findings from the stakeholder interviews included the relative invisibility of older women living with HIV and limited attention to their specific experiences, compounded by a challenging policy and funding environment. Additionally, diversity within the population of older women living with HIV and the intersection of ageism, sexism and HIV-related stigma emerged as key issues. Participants differed in their views on the specificity of women's experiences and the need for targeted approaches, but the value of a gendered approach was indicated.

The literature reviews, policy review and stakeholder interviews informed the design, conduct and analysis of the main qualitative data collected in this study, through participatory creative workshops with 18 older women living with HIV and life story interviews with 14 older women living with HIV. The data from these were brought together and analysed, including through a participatory analysis workshop in which four older women living with HIV reviewed data samples and generated themes, informing the analysis.

Analysis of women's narratives of ageing with HIV generated three themes: persistence; participation and personal connections; and, resilience. Women's experiences of ageing with HIV are shaped by intersecting identities, community responses and personal connections. Ageing with HIV brings challenges, added to and augmented by other difficulties women face in their lives, but women draw on individual and community assets in order to adapt, cope and thrive.

Belonging to a community of women living with HIV and a broader community of people living with HIV created a vital space of safety, in which women found support, advice and meaning. Supporting other women, in particular women diagnosed more recently or who were experiencing other challenges, provided a

sense of purpose for many women, both broadly in their lives, and in the specific process of finding meaning in HIV itself. Women's personal communities importantly included children, partners, family and friends, as well as women living with HIV. Each personal community was necessarily unique, and the role HIV played in blocking or expanding connections within each women's personal community varied.

Connections with other women living with HIV evoked both a personal and a political community for many women, who described belonging to a community of women living with HIV in terms of a political act, caring for others as a way of reclaiming a stigmatised identity and overcoming marginalisation (Emejulu and Bassel 2018). Participation was rooted in community belonging, providing emotional, social and practical support in a mutual, symbiotic process. I was struck by how often women, in interviews and workshops, talked about 'we' rather than 'I', defining HIV itself as a collective experience. This went beyond community formation as a response to stigma, and beyond the practical exchange of information to a full, positive account of a community based on shared identity but also on meaningful connections.

Common experiences were also important to sustaining this community, including diagnosis which had more parallels than might be predicted given the differences in when women were diagnosed during the epidemic. The impact of diagnosis was often disruptive to women's plans, relationships and wellbeing, even when effective treatment was available. However, there was a difference for women whose initial diagnosis was terminal, and who described the long-term impact of surviving when they had not expected to. 'Survivor conflict' captures the challenges and complex emotions of surviving, with women describing mixed feelings of luck, gratitude and also loss – of self, relationships, opportunities and possible futures. Surviving was not a return to a pre-existing life but adapting to a new life and changed identity, and this brought with it challenges that many women described as ongoing, even many years later. Similarly, adapting to an unexpected and unprepared for old age brought new challenges, including menopause, co-morbidities and loss. Ageing well with HIV was more complex than simply managing HIV treatment and care, and women described ongoing challenges with side effects and other health issues.

Coping with 'survivor conflict', HIV and other aspects of life was enabled and informed by assets, including community belonging, acceptance of HIV, 'sense of coherence' and 'resistance resources'. Access to and ability to benefit from these assets was informed, enabled or blocked by socio-economic issues, especially poverty and immigration status. An assets-based approach enabled my research to understand and explore women's own strengths and adaptations to coping with HIV, and informed a broader analysis that identified external barriers. Assets-based approaches are not intended to only explore the positive. Women's stories included loss, violence, poverty and bereavements that impacted their lives, wellbeing and coping. How women responded to and accommodated these challenges is important to understand, in particular to inform better support. Community played an important role for many women in coming through these difficult experiences.

Fragmentation of commissioning and reductions in services, both clinical and third sector, emerged as an important theme in stakeholder interviews, and this resonated in the stories of women living with HIV taking part in workshops and life story interviews. While the biomedical experience of HIV has transformed, to a manageable chronic condition with effective treatment, women ageing with HIV continue to struggle with treatment side effects, co-morbidities, concurrent health issues, and social stigma. Many also carry past experiences of trauma and disruption, and face poverty and social marginalisation, which biomedical approaches cannot solve. As indicated in stakeholder interviews, the role of the HIV clinic and especially the HIV consultant continues to be vital, as framing institution and agent, and as sources of support. Reduced appointment times and frequency are a source of concern for many older women living with HIV, who can struggle to access the support they need to manage their health, and in some cases appear to be struggling with side effects that are under-reported or accepted as normal.

The invisibility of women living with HIV in research and advocacy was also highlighted in stakeholder interviews and in the stories of women living with HIV themselves. Ageism, sexism and HIV-related discrimination can interact to decrease the visibility of older women living with HIV and to limit their involvement in research and advocacy. The UK HIV response is shaped by an epidemiological

approach that does not consider women as a group, and leads to research, services and data that do not focus on women as a class or on gender as a social structure impacting the experience of HIV. The form and impact of HIV stigma for many women is gendered, interacting with gendered ideas of appropriate behaviour for women and judgements formed based on these. Many women had experienced gender-based violence, in some cases linked to HIV acquisition directly.

Returning to the five elements of postmodern feminist research described by Cameron (2005) and presented in chapter four, in my analysis I focused on gender as locally explained in relation to specific contexts and diverse identities and social locations. Gender emerged differently in different women's accounts, though many shared similarities in relation to gendered expectations of motherhood as requiring a nurturing, self-sacrificial role. For women who were separated from their children by migration, this led to disruption in identity linked to feeling unable to perform their gendered role in line with their expectations. Similarly, some women who did not have children described both a personal sense of loss, and a socially-imposed sense of having failed to fulfil an expected role. Importantly, other women who did not have children described no such internal or external loss, and their experiences are critical to highlight as current evidence focuses on women living with HIV as mothers, failing to account for other experiences.

Women's understanding of community and their priority of care for others can also be read as gendered, as women often centred providing care and support as important to their own identity, which conforms to gendered expectations of women as caregivers. However, I would argue that conformity with gendered norms does not necessarily imply a limitation or restriction, when those norms are chosen as well as imposed. Women's evocation of the value of caring for others, whether peers living with HIV or children, was often described as a source of value, meaning and joy. There is not a straightforward conclusion to draw, given the reality that norms also curtail available options and no choice is made entirely freely, but drawing on an assets-based approach that values women's own accounts, suggests that the analysis put forward by Emejulu and Bassel (2018) has salience for women ageing with HIV.

Women's evocation of HIV as a collective, community experience stands in contradiction to theories of biomedical citizenship that suggest biomedicalisation involves a shift to an individualised, client-centred role of HIV patient (Paparini and Rhodes 2016). Treatment played a significant role in many women's lives, especially as experienced as side effects, but the technoscientific markers of viral load and undetectability featured infrequently in women's narratives, and living well with HIV was much more often defined in communitarian terms of belonging with and supporting others, and individual terms of feeling and doing well.

HIV as a shared experience indicates the social as well as individual elements of the 'politics of life itself' (Rose 2001). Biomedicalisation can incorporate community, but does individualise, and in this the narratives women shared differed from wider discourses on biomedicalisation. A recent study in Canada explored biosociality for gay and bisexual men, in the context of PrEP and treatment as prevention (Girard, Patten et al. 2018). Girard et al describe how, as HIV prevention progresses, gay men have responded and adapted to new concepts, with relationships and community ties shaped by HIV prevention. Both PrEP and undetectability offered new forms of biosocial identity, adopted by participants, in addition to older identities of positive and negative. This differs from the discourses that emerged in my research, in which pharmaceutical innovations were not prioritised, and prevention was rarely a concern. Women's biosocial identity was shaped by shared, communitarian experiences of support and care, rather than discourses of prevention, risk and responsibility.

10.2 Impact and implications

The main research question explored in this study was:

What are the experiences of women ageing with HIV in London? How are these experiences understood and expressed?

With further sub-questions:

- How are these experiences mediated by gender, sexuality, ethnicity, migration status and experiences, or other factors?

- How have women adapted to ageing with HIV, including experiences of age-related conditions and other co-morbidities, home and residential care, and economic and social issues?
- What assets do women hold and use to mediate their experiences, and in what ways are they used? Is the notion(s) of 'community' amongst these assets?
- How is the concept of 'community' relevant? What constructions of 'community' can we discern in the experiences, accounts given and discourses employed by older women living with HIV?
- How have collectivities of older women living with HIV, and others, responded to growing older with HIV, for example, through peer support and activism? Does this suggest a 'biomedical citizenship' and how might this function? How does this counteract or mediate notions of 'community' for women living with HIV?

My findings suggest that women's experiences of ageing with HIV are shaped by belonging to a community of women living with HIV and people living with HIV, and that intersecting identities and social locations impact on women's ability to cope successfully with HIV over time. Gender and migration status particularly influence women's experiences, by limiting options and shaping social stigmas. Women are experiencing co-morbidities and treatment side effects alongside the menopause, and are mostly coping well with this, but their experiences are worsened by uncertainty, which both limits the support and information available to them, and represents a psychological burden limiting women's sense of being able to cope. Participants in my study were not yet receiving home or residential care, but many looked to this as a concern for the future, with concern rooted in loss of control (over individual choices, treatment and talking about HIV) with stigma also a worry.

Women hold a range of assets that support their ability to cope with HIV, with community foremost among these. Other assets include values, interests, inner strength, feeling in control, learning from age and experience, feeling able to make choices and plan for the future, and acceptance of HIV. Moving from the shock of diagnosis to accepting HIV and planning for the future is shaped and informed by framing institutions and agents, most importantly the community of

women living with HIV. The political form of community, and advocacy within it, is defined through shared identity, claiming a common experience, rejecting societal stigma and care for others with HIV. This suggests a collective response to HIV and shared HIV identity that counteracts individualised conceptions of biomedical citizenship.

The implications of these findings include the ongoing need for investment in HIV support services, recognising the vital role these play in providing the framework through which HIV community operates. It also indicates a need to review and reconsider how such services are provided, with a desire articulated by some older women living with HIV for more informal, open and social activities, in contrast to the formalised structure of support with a defined start and end point that is increasingly common, as noted by Squire (2013).

For women diagnosed prior to access to effective HIV treatment (either pre-1997, or diagnosed in a geographic location without accessible treatment), the burden of 'survivor conflict' is significant, and indicates a need for further, specialised support. There is also a huge amount to learn from these experiences, which are unique in the context of HIV but may have parallels for other health conditions.

The shock of diagnosis was described in similar terms by women diagnosed at very different stages of the epidemic, indicating the lack of knowledge about HIV and treatment in the wider population, and a need for more support at diagnosis. Involving women living with HIV in providing this support would be invaluable, as demonstrated by the prevalence in women's stories of meeting and being supported by other women living with HIV as the pivotal moment in learning to adapt to HIV.

The experiences of older women living with HIV are under-addressed and under-recognised, and while this study has aimed to fill the gap in literature, there is much work still to be done. In the context of cuts to services and funding, there is an urgent need to ensure that needs are understood but also to explore how individuals and communities are coping, and where this can be better supported. Importantly, this should include community, and not just an individualised understanding of what it means to live and age with HIV.

In June 2019, I held a small event to share the findings of this research with women living with HIV, researchers, advocates and other stakeholders from the HIV sector. Attendees included women who had participated in different phases of the research. Reflecting on the findings, older women living with HIV, as part of a panel discussion, highlighted key implications and resonances with their own experiences. This included a shared understanding of support as a mutually beneficial process for women living with HIV, and the focus on emotional and social support over more political forms of advocacy. Women's experiences of side effects, and hesitancy in raising concerns about them, also resonated for event attendees. As part of the event, attendees reviewed and revised recommendations (included in this section and the following section) and a plain English summary (Appendix 12) and worked with a graphic designer who is also a woman living with HIV to develop a set of creative memes to support dissemination of the research findings (forthcoming).

10.3 Additional research implications

Through this research, I sought to understand the experiences of women ageing with HIV. Given the paucity of research on women's experiences, I aimed to focus specifically on women and the role of gender in their experiences. There are a range of possible future directions in which to take this research forward.

This study could have been improved by recruiting more women aged 60 and over, and more women diagnosed recently with HIV, so further research including more women from each group would be beneficial.

The concept of 'survivor conflict' warrants further research, to understand more its resonance to older women living with HIV and how it is experienced. Additionally, understanding more how women can be supported to cope with 'survivor conflict' would be valuable.

Comparative study with men, in settings other than London (including both other UK settings and other countries) and women ageing with other health conditions would all potentially be of value.

The impact of side effects, pain and menopause were significant for many women, and additional research to explore both how these are experienced and how women might be better supported, would be recommended.

10.4 Reflections

So I have done that and I feel really, I feel proud, I feel happy, I feel I've been given a chance. [Laughs] Yeah. I was not meant to be here, and I'm still here.

Patricia's words captured both how women are coping and living well as they age with HIV, and the challenges they continue to face. They stuck with me after I transcribed her interview, or at least, they almost did. In my memory, and my thoughts as I began the analysis process, 'and', became 'but'. *I was not meant to be here, but I'm still here*. I thought of overcoming, of a sense of entering battle and winning. Then, re-reading the transcript, I realised my mistake. Not 'but', not overcoming, not a turning point excluding or negating the first part of the sentence. Instead, 'and', a sense of both parts mattering, both being included.

The stories I gathered and told in this research are stories of 'and', of living through difficult experiences and living on despite them. Of finding community with women joined by a shared virus and shared stigma, but so much more than that. Women's stories included needs, but also provided insights into how they were living well and assets they had realised, found and built in order to do so.

I set out as an advocate doing research, and wanted to be a researcher doing advocacy. Researching the experiences of women ageing with HIV as an act of recognition, discursive production and to achieve social change. I did so recognising my own role within a community of women *and* HIV and my own personal commitment to advocacy. In the four years that I have spent undertaking this research, I have developed a more nuanced understanding of the researcher-advocate role, learning that advocacy is interlinked and inseparable to research conducted with a feminist and participatory approach, and recognising the advocacy imperatives driving participants in research as well as researchers. Engaging with the theory of community and participation has informed and transformed my own position in important ways. I started out thinking of the

community of women living with HIV as something from which I was separated, but came to see the multiple identities and social locations that shape individual experiences, and how sharing some of these drives connection and belonging even where not all are shared. That community can also impose limits, on what is told and how it is told, is also important, and reflects a more critical engagement with community than I began this process with. Necessary and imposed silence and secrets, especially around HIV acquisition and at diagnosis, demonstrate framing agents and institutions participating in creating expectations of stigma, which become inevitable in response.

In my analysis, the feminist tenet that the 'personal is political' was key. Women's political engagement rested in care for others, and valuing personal connections. Research, too, is personal. Hearing the life stories of the 14 women who shared them with me changed me as a person, as well as a researcher. Stories are used to share wisdom, and I gained from this. During the course of this research, I turned 30, got married and have now spent half my working life as a PhD student. As I write this conclusion, I am pregnant with my first child. All these personal and professional experiences have been influenced by this research. In telling me their stories, of surviving, dealing with challenges, mothering, loving and supporting their communities, personal and political, each woman I met in this study influenced my own ability to do the same. My role as advocate, researcher, and member of this wider community of women *and* HIV have all shaped who I have become.

As HIV becomes increasingly normalised as a chronic condition, its social meaning continues to be informed by both the social stigma it still attracts, and the shared experience and identity it creates in many women living with it. Women continue to face the "violence of invisibility". In this research, I have sought to address that through transforming the way women ageing with HIV are understood, centring their stories and voices and involving older women living with HIV in epistemic production. Through methodological and epistemological innovation, and a phased, iterative approach to data collection and analysis, I have presented new insights into women's experiences of ageing with HIV, discourses of community and participation, and resilience.

In much the same way as a story requires an ending, there is a push towards the 'end of HIV' or 'end of AIDS', both phrases used in global and national targets, journal articles, media coverage and conferences with increasing frequency in recent years. Yet in the lives of people living with HIV, there will be no end to HIV. The story does not have a tidy ending. Thanks to advances in HIV treatment, HIV is now manageable, but managing is difficult. Treatment has improved massively, but side effects persist and limit many women's lives. Side effects are significantly reduced compared to early treatment, but less is not zero. Social attitudes to HIV are more informed and less stigmatising, but ignorance and stigma persist. Life expectancy with HIV is near normal, but ageing with HIV is uncertain and challenging. Reaching an undetectable viral load is not the end of the HIV story, but an ongoing state to maintain, which takes effort, both emotional and practical.

Women's stories, shared with me in this research, demonstrated that there is no easy narrative of ageing with HIV. There is no hero defeating an opponent or completing a quest. There are elements of tragedy and comedy. Relationships, social positions and knowledge can be gained and also lost. HIV had impacted women's stories in different ways, though diagnosis was almost always experienced as a shock and disruption, women adapted to it differently, and often other difficult experiences were understood as having a more negative impact. The futures women looked forward to included uncertainty and worry but also joyful and desired experiences and events. Women were often living well and expected to continue to do so. That is not to imply a happy ending. There is no ending. Women persist.

APPENDICES

Appendix 1: Screening outcomes for systematic review

No.	Title	Authors	Include?	Reason if excluded
1.	Elderly women with human immunodeficiency virus infection: Is there an effect of the virus on neuropsychological profile?	Sorlini et al	No	Quantitative
2.	The association between HIV status and homelessness among veterans in care.	Ghose et al	No	Focus on veterans, not relevant.
3.	Taking it one day at a time: African American women aging with HIV and co-morbidities.	Warren-Jeanpiere et al	Yes	
4.	Impact of a secondary prevention intervention among HIV-positive older women.	Echenique et al	No	Prevention intervention.
5.	Select neurocognitive impairment in HIV-infected women: Associations with HIV viral load, hepatitis C virus, and depression, but not leukocyte telomere length.	Giesbrecht et al	No	Clinical.
6.	HIV Testing Among Midlife Women in the Deep South: An analysis of the 2008 Behavioral Risk Factor Surveillance System Survey data.	Wigfall et al	No	Quantitative study, Focus on testing.
7.	Frequency and correlates of late presentation for HIV infection in France: Older adults are a risk group—Results from the ANRS-VESPA2 Study, France.	Wilson et al	No	Quantitative study, Focus on testing.
8.	HIV, aging, and advance care planning: Are we successfully planning for the future?	Erlandson et al	No	Quantitative study.
9.	Intimacy and sexual decision making: Exploring the perspective of HIV positive women over 50.	Psaros et al	Yes	
10.	Typology of older female sex workers and sexual risk for HIV infection in China: A qualitative study	Hao et al	No	Research in China
11.	The association between depressive symptoms, anger, and perceived support resources among underserved older HIV positive Black/African American adults.	Whitehead et al	No	Quantitative Study
12.	Is quality of life poorer for older adults with HIV/AIDS? International evidence using the WHOQOL-HIV.	Skevington et al	No	Quantitative Study

13.	Despondency among HIV-positive older men and women in Uganda.	Wright	No	Research in Uganda
14.	Life transition with HIV: Some observations of the phenomenon of growing older with the infection	Lawrence et al	No	Only 1 female (in sample of 8)
15.	Soluble and cell-associated insulin receptor dysfunction correlates with severity of HAND in HIV-infected women.	Gerena et al	No	Clinical, quantitative
16.	Prevalence of HIV among those 15 and older in rural South Africa.	Gómez-Olivé et al	No	Study in South Africa
17.	Aging with HIV and disability: The role of uncertainty.	Solomon et al	Yes	
18.	Prevalence and predictors of posttraumatic stress disorder and depression in HIV-infected and at-risk Rwandan women.	Cohen et al	No	Study in Rwanda
19.	Age, stress, and isolation in older adults living with HIV.	Webel et al	No	Quantitative
20.	Attention HIV: Older African American women define sexual risk.	McCord et al	No	Prevention focus
21.	Loneliness and HIV-related stigma explain depression among older HIV-positive adults.	Grov et al	No	Quantitative
22.	Health disparities among lesbian, gay, and bisexual older adults: Results from a population-based study.	Fredriksen-Goldsen et al	No	Quantitative
23.	Sexual minority women and depressive symptoms throughout adulthood.	Pyra et al	No	Quantitative
24.	'Older women', customary obligations and orphan foster caregiving: The case of queen mothers in Manya KLO, Ghana.	Drah et al	No	Study in Ghana
25.	A randomized clinical trial of a coping improvement group intervention for HIV-infected older adults.	Heckman et al	No	Quantitative
26.	'My legs affect me a lot. ... I can no longer walk to the forest to fetch firewood': Challenges related to health and the performance of daily tasks for older women in a high HIV context.	Schatz et al	No	Study in South Africa
27.	HIV-positive mothers with late adolescent/early adult children: 'Empty nest' concerns.	Murphy et al	Yes	
28.	Clinical and behavioural aspects of aging with HIV infection.	Sherr et al	No	Quantitative
29.	Protective and risk factors associated with stigma in a population of older adults living with HIV in Ontario, Canada.	Emlet et al	No	Quantitative

30.	Caregiving responsibilities and burden among older people by HIV status and other determinants in Uganda.	Mugisha et al	No	Study in Uganda
31.	'It's a hidden issue': Exploring the experiences of WLWH-associated neurocognitive challenges using a disability framework.	Gallagher et al	Yes	
32.	Entry and re-entry into informal care-giving over a 3-year prospective study among older people in Nairobi slums, Kenya.	Chepngeno-Langat et al	No	Study in Kenya
33.	LGBT people's knowledge of and preparedness to discuss end-of-life care planning options.	Hughes et al	No	Focus on specific health policy in Australia
34.	Place of death among Botswana's oldest old.	Lazenby et al	No	Study in Botswana
35.	Midlife sexuality among Thai adults: Adjustment to aging in the Thai family context.	Ford et al	No	Study in Thailand
36.	Drug use and loneliness are linked to unprotected sex in older adults with HIV.	Kott	No	Quantitative
37.	A new frailty syndrome: Central obesity and frailty in older adults with the human immunodeficiency virus.	Shah et al	No	Clinical study
38.	Providers caring for adolescents with perinatally-acquired HIV: Current practices and barriers to communication about sexual and reproductive health.	Albright et al	No	Focus on adolescents
39.	Gender differentials on the health consequences of care-giving to people with AIDS-related illness among older informal carers in two slums in Nairobi, Kenya.	Chepngeno-Langat et al	No	Study in Kenya
40.	Sexual behaviour and diagnosis of people over the age of 50 attending a sexual health clinic.	Bourne et al	No	Clinical, quantitative
41.	Newly diagnosed epileptic seizures: Focus on an elderly population on the French island of Reunion in the Southern Indian Ocean.	Tchalla et al	No	Study in Reunion
42.	Changing masculinities: Land-use, family communication and prospects for working with older men towards gender equality in a livelihoods intervention.	Jobson et al	No	Focus on men, not relevant research
43.	Experiences and perceptions of HIV/AIDS and sex among people with disabilities in Windhoek, Namibia.	Van Rooy et al	No	Study in Namibia

44.	Effect of depressive symptoms and social support on weight and CD4 count increase at HIV clinic in Ethiopia.	Alemu et al	No	Study in Ethiopia
45.	Older African Americans' management of HIV/AIDS stigma.	Foster et al	Yes	
46.	Acceptability and factors associated with willingness to receive short messages for improving antiretroviral therapy adherence in China.	Xiao et al	No	Study in China
47.	A C17T polymorphism in the mu opiate receptor is associated with quantitative measures of drug use in African American women.	Crystal et al	No	Clinical research
48.	Relationship of ethnicity, age, education, and reading level to speed and executive function among HIV+ and HIV- women: The Women's Interagency HIV Study (WIHS) Neurocognitive Substudy.	Manly et al	No	Quantitative
49.	Grandparents fostering orphans: Influences of protective factors on their health and well-being.	Mhaka-Mutepfa et al	No	Quantitative
50.	Changing household composition and food security among the elderly caretakers in rural Western Kenya.	Muga et al	No	Study in Kenya
51.	Beyond sexual desire and curiosity: Sexuality among senior high school students in Papua and West Papua Provinces (Indonesia) and implications for HIV prevention.	Diarsvitri et al	No	Study in Indonesia
52.	HIV providers' perceptions of and attitudes toward female versus male patients.	Blackstock et al	No	Focus on provider experiences
53.	Development of normative neuropsychological performance in Thailand for the assessment of HIV-associated neurocognitive disorders.	Heaps et al	No	Quantitative
54.	People living with serious illness: Stories of spirituality.	Molzahn et al	No	Focus on illness overall not HIV specific
55.	Women's views regarding hypnosis for the control of surgical pain in the context of a randomized clinical trial.	Marc et al	No	Focus not on HIV or older women

Appendix 2: Critical appraisal of included results of systematic review

Critical summary of all included results:

Author/ date	Aim of study/paper	Type of study	Main findings & conclusions	Strengths and limitations
Emlet, 2006	To explore whether older adults with HIV experience both ageism and HIV-related stigma and what these experiences are.	Semi-structured interviews	68% experienced ageism and HIV stigma, with the experiences often separate. Key themes included “rejection, stereotyping, fear of contagion, violations of confidentiality, and internalized ageism.”	Valuable in focus on ageism and HIV stigma. 32% women participants. Study is 10 years old and based in US, both limitations.
Foster & Gaskins, 2009	Explore experiences and management of HIV-related stigma among older African American people living with HIV	Focus groups and validated stigma surveys	Four main themes that emerged were: disclosure, experiences of stigma, need for HIV information and education, and acceptance of HIV. Most stigma experienced was related to internalised shame rather than direct stigma.	29.2% women in study. Focus in economically deprived South of the US, with African American participants, so experiences not necessarily transferable or generalisable.
Gallagher et al, 2013	Explore the experiences of WLWH and with self-identified neurocognitive challenges using the World Health Organization’s International Classification of Functioning, Disability and Health (ICF)	Semi-structured interviews	Impairments such as memory loss or difficulty completing multiple tasks, and the impact of neurocognitive challenges on participation in roles such as work and parenting, were perceived to have a bigger impact than challenges in completing activities.	Focus on women and on experiences of neurocognitive challenges is unusual and so study is valuable. Also quite recent. Canadian study.
Murphy et al, 2012	To explore the experiences of ‘empty nest’ syndrome amongst	Semi-structured interviews	Challenges associated with the experience of children leaving home included loss	Specific focus on ‘empty nest’ experiences and recruited from one US state, so

	mothers living with HIV, through their own experiences and narratives.		of social support, loss of identity and financial impact, whilst hopes for the future included self-improvement, travel and romantic partners.	limited value but experiences may be transferable.
Power, 2010	Explore the social impact of ageing with HIV for people living with HIV in the UK, focused on social care needs.	Qualitative, survey and individual interviews	Concerns include financial difficulties, housing, employment, self-care and loneliness. Ranking of concerns varies between groups.	Large study with UK sample, representative inclusion of women. Limitations include lack of reflexivity, especially as community researchers involved. Also, analysis is grouped by 'black African women' and 'white heterosexuals' so no overall picture of women's experiences.
Psaros et al, 2012	To explore factors affecting intimate partner relationships for older WLWH.	In-depth individual interviews	Three major themes emerging from the study were stigma, body image, and disclosure. Women described a sense of 'hopelessness' around intimate partnerships which suggests a need for targeted support interventions to negotiate such relationships.	Strengths include specific focus on women. Interesting focus on intimacy and sexual relationships. Study in Boston, US.
Rosenfeld, 2015	Explore social support, mental health and quality of life of older people living with HIV in London	Life-history and focus group interviews, and validated surveys	Older people living with HIV have similar concerns to younger people living with HIV around stigma, isolation and disclosure, but also have specific concerns linked to older age: ageism and its intersection	Large study with London cohort and women included. Utilises life history methodologies. But analysis grouped by 'black African heterosexual men and women' and 'white

			with HIV stigma, disclosure to children and grandchildren, uncertainty over HIV and ageing, relationships and economic coping.	heterosexuals' so no clear picture of experiences of women overall.
Schrimshaw & Siegel, 2003	Explore barriers to receiving social support from family and friends, as perceived and described by older people living with HIV.	Semi-structured interview	Many participants reporting that they did not receive sufficient social support, with barriers including disclosure, desire for independence, and ageism. These and other barriers may underpin social isolation among older people living with HIV.	US sample, more than 10 years old, but 29% women.
Shippy & Karpiak, 2005	To explore the social networks of older people living with HIV in New York.	Social support survey using various measures	Participants were isolated from informal social networks due to HIV-related stigma and ageism. Most lived alone and/or did not have an intimate partner, relying on friends for social support. Many of these friends were also living with HIV. The social networks of older people living with HIV are fragile, and absent of traditional sources of care.	Valuable for this research as focuses on social networks. Includes 34% women. Limitations are that this was conducted more than 10 years ago and conducted in US.
Solomon et al, 2014	To describe the role that uncertainty linked to HIV plays and how this contributes to the experience of disability among older	In-depth interviews.	Participants described the episodic and therefore unpredictable nature of HIV as contributing to uncertainty. Age also generated uncertainties, around health challenges, the	Recent study with about 40% women participating. Conducted in Canada so transferability questions.

	people living with HIV.		knowledge and ability of healthcare providers, finances, housing and care.	
Warren-Jeanpiere et al, 2014	Explore self-management of co-morbidities in older African American WLWH.	Focus groups	Difficulties managing co-morbidities were attributed to challenges such as lack of insurance, financial problems and work schedules rather than ageing. HIV self-management has to be addressed in this wider context and include management of co-morbidities to meet the needs of an ageing cohort.	Particular focus on gender norms including racialized gender norms and impact on coping and self-management is a strength, but there are limitations to this as it is a US study, specifically looking at experiences of African American women.

Critical appraisal of each result:

A national study of ageing and HIV (*50 Plus*) (Power, Bell et al. 2010)

Was there a clear statement of the aims of the research?	Yes, with respect to the policy and social need for improved evidence. Research aims and questions somewhat less clear.
Is a qualitative methodology appropriate?	Yes
Was the research design appropriate to address the aims of the research?	Yes – included both survey and qualitative interviews, broad exploration of needs and priorities
Was the recruitment strategy appropriate to the aims of the research?	Yes in that recruited large sample and aims were related to people living with HIV overall
Was the data collected in a way that addressed the research issue?	Yes
Has the relationship between researcher and participants been adequately considered?	No – study conducted by both third sector staff and community researchers (people living with HIV) but these relationships have not been addressed in the report.
Have ethical issues been taken into consideration?	Not specifically addressed in the report. Advisory committee of people living with HIV. Community researchers.
Was the data analysis sufficiently rigorous?	Yes
Is there a clear statement of findings?	Yes

How valuable is the research?	Valuable, partly due to sample, and also due to breadth of findings. Missed opportunity in terms of community research though. Also, analysis grouped by black African women and white heterosexuals so no overall picture of women's experiences. 81 (19.8%) women participants – 19.3% of people over 50 living with HIV at time of study were women
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Social support, mental health, and quality of life among older people living with HIV: Findings from the HIV and Later Life (HALL) project (Rosenfeld, Anderson et al. 2015)

Was there a clear statement of the aims of the research?	Yes
Is a qualitative methodology appropriate?	Yes
Was the research design appropriate to address the aims of the research?	Yes included mixed methods with qualitative to capture experiences and surveys using validated quality of life measures
Was the recruitment strategy appropriate to the aims of the research?	Yes – both clinics and community-based organisations supported recruitment
Was the data collected in a way that addressed the research issue?	Yes
Has the relationship between researcher and participants been adequately considered?	No – not explicitly addressed in report
Have ethical issues been taken into consideration?	Yes – describes ethical approval process and efforts to maintain confidentiality. Advisory committee of people living with HIV.
Was the data analysis sufficiently rigorous?	Yes
Is there a clear statement of findings?	Yes
How valuable is the research?	Valuable in terms of approach (life history interviews among other methods) and women included. But analysis grouped by black African heterosexual men and women and white heterosexuals

“You’re awfully old to have this disease”: Experiences of stigma and ageism in adults 50 years and older living with HIV/AIDS. (Emlert 2006)

Was there a clear statement of the aims of the research?	Yes – very clear statement of evidence gap around ‘double jeopardy’ of HIV stigma and ageism
Is a qualitative methodology appropriate?	Yes, as focus is on exploring experiences
Was the research design appropriate to address the aims of the research?	Yes

Was the recruitment strategy appropriate to the aims of the research?	Yes
Was the data collected in a way that addressed the research issue?	Yes
Has the relationship between researcher and participants been adequately considered?	It is considered in relation to analysis of the data, coding and defining themes. Not specifically within the research encounter itself.
Have ethical issues been taken into consideration?	Yes
Was the data analysis sufficiently rigorous?	Yes – multiple phases of analysis conducted and described in detail
Is there a clear statement of findings?	Yes
How valuable is the research?	Valuable in focus on ageism and HIV stigma. Study is 10 years old and based in US, both limitations. 32% women participants.

Older African Americans' management of HIV/AIDS stigma (Foster and Gaskins 2009)

Was there a clear statement of the aims of the research?	Yes, reasonably clear – understanding experiences of stigma and strategies for dealing with it.
Is a qualitative methodology appropriate?	Yes
Was the research design appropriate to address the aims of the research?	Yes – mixed methods with focus groups and supplementary validated survey instruments
Was the recruitment strategy appropriate to the aims of the research?	Yes – AIDS Service Organisations actively recruited, purposive sampling.
Was the data collected in a way that addressed the research issue?	Yes
Has the relationship between researcher and participants been adequately considered?	No
Have ethical issues been taken into consideration?	Yes
Was the data analysis sufficiently rigorous?	Yes
Is there a clear statement of findings?	Yes
How valuable is the research?	29.2% women in study. Focus in economically deprived South US, with African Americans so experiences not necessarily transferable.

“It’s a Hidden Issue”: Exploring the experiences of WLWH-associated neurocognitive challenges using a disability framework (Gallagher, Biro et al. 2013)

Was there a clear statement of the aims of the research?	Yes – both of the need for in-depth qualitative research on subjective experiences of living with HIV-associated neurocognitive challenges, and on
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	the need for specific research with women – under-represented in existing research, and likely to experience differently
Is a qualitative methodology appropriate?	Yes
Was the research design appropriate to address the aims of the research?	Yes
Was the recruitment strategy appropriate to the aims of the research?	Yes – particularly as self-identified as having neurocognitive challenges
Was the data collected in a way that addressed the research issue?	Yes
Has the relationship between researcher and participants been adequately considered?	No – notes who the researchers are but no consideration of research relationship (especially lacking given researchers conducting interviews and analysing data were primarily Masters students, perhaps with less experience in research)
Have ethical issues been taken into consideration?	Yes – as well as ethical review also describes process of consent and expenses paid
Was the data analysis sufficiently rigorous?	Yes
Is there a clear statement of findings?	Yes
How valuable is the research?	Focus on women and on experiences of neurocognitive challenges is unusual and so study is valuable. Also quite recent.

HIV-positive mothers with late adolescent/early adult children: “empty nest” concerns (Murphy, Roberts et al. 2012)

Was there a clear statement of the aims of the research?	Yes
Is a qualitative methodology appropriate?	Yes
Was the research design appropriate to address the aims of the research?	Yes
Was the recruitment strategy appropriate to the aims of the research?	Drawn from a wider longitudinal study, random sample from a larger study sample.
Was the data collected in a way that addressed the research issue?	Yes
Has the relationship between researcher and participants been adequately considered?	No
Have ethical issues been taken into consideration?	Yes
Was the data analysis sufficiently rigorous?	Rigorous but uses counting and percentages with qualitative data

Is there a clear statement of findings?	Yes
How valuable is the research?	Specific focus on 'empty nest' experiences and recruited from one US state, so limited value but experiences may be transferable.

Intimacy and sexual decision making: exploring the perspective of HIV positive women over 50 (Psaros, Barinas et al. 2012)

Was there a clear statement of the aims of the research?	Yes in particular on impact of age and HIV status on physical and emotional aspects of forming and conducting intimate relationships
Is a qualitative methodology appropriate?	Yes
Was the research design appropriate to address the aims of the research?	Yes
Was the recruitment strategy appropriate to the aims of the research?	Yes – used community organisations, referrals by healthcare providers, and also information provided after screening for an RCT with similar inclusion criteria
Was the data collected in a way that addressed the research issue?	Yes
Has the relationship between researcher and participants been adequately considered?	No
Have ethical issues been taken into consideration?	Yes
Was the data analysis sufficiently rigorous?	Yes
Is there a clear statement of findings?	Yes
How valuable is the research?	Study in Boston, US. Focused on women. Interesting focus on intimacy and sexual relationships.

Perceived Barriers to Social Support from Family and Friends among Older Adults with HIV/AIDS (Schrimshaw and Siegel 2003)

Was there a clear statement of the aims of the research?	Yes, clear on lack of research among older adults with HIV on links between social support and psychological wellbeing
Is a qualitative methodology appropriate?	Yes
Was the research design appropriate to address the aims of the research?	Yes
Was the recruitment strategy appropriate to the aims of the research?	Yes
Was the data collected in a way that addressed the research issue?	Yes

Has the relationship between researcher and participants been adequately considered?	No
Have ethical issues been taken into consideration?	Not mentioned
Was the data analysis sufficiently rigorous?	Yes
Is there a clear statement of findings?	Yes
How valuable is the research?	US sample, more than 10 years old. 29% women.

The aging HIV/AIDS population: fragile social networks (Shippy and Karpiak 2005)

Was there a clear statement of the aims of the research?	Yes, highlights the limited evidence around social networks and older adults living with HIV, and the impact of lack of social support on mental and psychological health.
Is a qualitative methodology appropriate?	Yes
Was the research design appropriate to address the aims of the research?	Yes (social network analysis)
Was the recruitment strategy appropriate to the aims of the research?	Yes – both ACRIA database and community organisations
Was the data collected in a way that addressed the research issue?	Yes
Has the relationship between researcher and participants been adequately considered?	No
Have ethical issues been taken into consideration?	Refers to informed consent but not other issues
Was the data analysis sufficiently rigorous?	Yes
Is there a clear statement of findings?	Yes
How valuable is the research?	Older research. 34% women. Study in US.

Aging with HIV and disability: the role of uncertainty (Solomon, O'Brien et al. 2014)

Was there a clear statement of the aims of the research?	Yes – specifically the interaction between uncertainty and experiences of disability, the uncertainty associated with HIV and the lack of research on this with a focus on older people
Is a qualitative methodology appropriate?	Yes
Was the research design appropriate to address the aims of the research?	Yes
Was the recruitment strategy appropriate to the aims of the research?	Yes

Was the data collected in a way that addressed the research issue?	Yes
Has the relationship between researcher and participants been adequately considered?	No
Have ethical issues been taken into consideration?	Refers to ethical approval. Advisory committee of people living with HIV.
Was the data analysis sufficiently rigorous?	Yes
Is there a clear statement of findings?	Yes
How valuable is the research?	Canadian study. Recent. About 40% women.

Taking It One Day at a Time: African American Women Aging with HIV and Co-Morbidities (Warren-Jeanpiere, Dillaway et al. 2014)

Was there a clear statement of the aims of the research?	Yes – research gap on self-management of co-morbidities and in HIV and ageing research that focuses on age identity rather than chronological or biological age
Is a qualitative methodology appropriate?	Yes
Was the research design appropriate to address the aims of the research?	Yes (single-category focus groups)
Was the recruitment strategy appropriate to the aims of the research?	Yes – purposive sampling of women from the Washington DC Women’s Interagency HIV Study (WIHS)
Was the data collected in a way that addressed the research issue?	Yes
Has the relationship between researcher and participants been adequately considered?	No
Have ethical issues been taken into consideration?	Yes, approval is discussed
Was the data analysis sufficiently rigorous?	Yes
Is there a clear statement of findings?	Yes
How valuable is the research?	US study, specifically looking at experiences of African American women. Particular focus on gender norms including racialized gender norms and impact on coping and self-management

Appendix 3: Thematic summary of social science literature review

This is a summary of findings from a systematically approached review of the social science literature on women, ageing and HIV. It considered the health and social care needs of older women living with HIV including needs and experiences related to ageing with HIV. The review process included a key word search of relevant databases and included 11 relevant articles and reports. Nine themes emerged overall.

Social networks and relationships: intimate partners, family and friends

HIV can have a significant impact upon both social networks and relationships, through the impact of discrimination or non-disclosure causing disruption to relationships, including preventing them from forming or continuing. Fears around the consequences of disclosure prevent many older people living with HIV from seeking and accessing support from friends, partners and family. Relationships with children, intimate partners, parents, and friends can all be affected. Many women avoid intimate partnerships to avoid disclosure or discrimination/negative experiences.

Mental health, wellbeing and coping

Ageing with HIV can have an impact on mental health, including increasing experience of symptoms of anxiety and depression. The mental health impact of HIV diagnosis varies according to when an individual was diagnosed (e.g. whether treatment was available) and knowledge/experience of HIV prior to diagnosis. Coping strategies include accepting HIV and learning to live with it rather than focussing on it, as well as spirituality/religion and having a positive outlook. Practical coping includes strategies to deal with forgetfulness like writing lists, and activities such as volunteering, especially in HIV support organisations.

Care and social support

The prospect of requiring formal care, or entering a care home, was a source of significant anxiety, with participants in multiple studies citing concern over discriminatory treatment from care staff as a worry as they grow older. Formal HIV support services, especially peer support groups, were frequently cited as vital sources of social support, particularly support that is informed by shared experiences, though some felt more tailored support for older women was

needed. In some studies, participants reported receiving insufficient social and/or practical support. Disclosure can be a barrier to accessing support.

Loneliness and isolation

Loneliness and isolation recur frequently as themes throughout the included texts, linked often to small social networks and lack of social support. Some participants described having no friends, while others faced practical barriers to participate in social or community life that led to them feeling isolated. These experiences of loneliness and isolation led women to seek and value peer support and social contact with other women living with HIV, though this was not always available.

Stigma and discrimination

Overall, stigma and discrimination, both actually experienced, and somewhat more commonly, anticipated, featured across many of the included studies. Experiences or expectations of stigma and discrimination lead some older women living with HIV to limit disclosure and practise 'protective silence'. One study found that most participants reported that they rarely or did not experience stigma at all, except on the rating of internalised stigma. This self-stigma influenced behaviour around disclosure.

Health needs and co-morbidities

Participants in many of the different studies described difficulties in managing HIV alongside other conditions, as well as with concurrent health related needs such as menopause. Whilst HIV itself was for most people managed by medication, side effects from these treatments were a health issue in themselves. The episodic nature of HIV made it more challenging to manage. Difficulty in ascribing symptoms to ageing, HIV, other conditions or menopause was common amongst women, and this uncertainty was itself felt to be difficult to manage.

Socio-economic and practical issues

A range of socio-economic and practical issues caused, exacerbated or complicated by HIV emerged as significant to the experience of ageing with HIV. This included work – both the social value of work as a form of connection and interaction, and challenges with managing work when experiencing poor health, treatment side effects, and older age. Immigration was also a key issue.

Managing bills, food and other daily costs was challenging for participants dependent on benefits.

Disclosure

Disclosure is closely associated with relationships and social support, but also emerged independently as a source of uncertainty and concern. Levels of disclosure varied. Decisions about disclosure were influenced by factors including the potential impact on the relationship, the practical benefits of disclosure, and judgments of the knowledge and views of HIV held by the other person. Other people living with HIV were seen as the safest people to disclose to as they were expected to be non-stigmatising, informed and to understand the need for confidentiality.

Ageism

In addition to HIV-related stigma and discrimination, some studies showed evidence of ageism. Some participants felt that HIV stigma had worsened with age, and in others participants felt they had experienced discrimination linked to both age and HIV status. Others though suggested they did not think that stigma had increased as they got older.

Appendix 4: Topic guide for participatory literature review

1 hour call, by Skype, recorded.

- 1) Introductions, describe process, agree to recording and notes, and discuss anonymity. (5 minutes)
- 2) Overview of summary of literature review – describe review process and summarise key findings. (5 minutes)
- 3) Discussion: (40 minutes)
 - a. Do these themes reflect what you would expect to be in the literature?
 - b. Does this echo and reflect your own experiences – do you see your own experiences in this?
 - c. What isn't included? Are there any gaps?
 - d. What do you think could be added or explored further?
 - e. Why do you think there are gaps? What influences the themes that are and are not reflected in the literature?
- 4) Conclusions, summarise key points and describe next steps e.g. inclusion in thesis and influence on workshops and life story interviews. (5 minutes)
- 5) Opportunities for further involvement – interested in co-authoring an article to present these findings? And also welcome to participate in life story interviews. (5 minutes)

Appendix 5: Indicative format and questions for participatory workshops

Item	Details	Time	Facilitator
Introduction	<ul style="list-style-type: none"> • Researcher introduces herself and gives a broad introduction to the project • Outline the workshop structure and content • Invite participants to introduce themselves, with an icebreaker activity 	5 mins	
Ground rules	<ul style="list-style-type: none"> • Researcher outlines the necessity of confidentiality. Details how this will be protected within the research, and invites ideas on how participants can respect confidentiality. • Group discussion on ground rules including on not interrupting, respecting others, recognising the value in different views and experiences and maintaining confidentiality within and after the group. 	5 mins	<i>Write up on flipchart, to display throughout workshop</i>
Definitions	<ul style="list-style-type: none"> • Discussion of what ageing means – sharing ideas and word association 	5 mins	<i>Flipchart</i>
Initial discussion	<ul style="list-style-type: none"> • What does ageing with HIV mean? Split into smaller groups to discuss and develop a list of positive and negative aspects of ageing. • Whole group discussion to share group outcomes and highlight any gaps 	10 mins	<i>Flipchart</i>
Visual activity	<ul style="list-style-type: none"> • Using visual methodology to describe and illustrate experiences of ageing with HIV (possibly using body mapping methodologies) – in small groups • Presenting the visual outcomes and discussion 	45 mins	<i>A3 paper and creative materials</i>
Needs and services	<ul style="list-style-type: none"> • Based on experiences shared – what are the needs of women ageing with HIV, what services are needed and what are the challenges? • Further discussion of how the participants are currently meeting their needs and dealing with challenges they have identified. 	10 mins	
Specificity	<ul style="list-style-type: none"> • Do you think these issues are specific to <i>women living with HIV</i>? Or specific to HIV? What other things might influence them? 	10 mins	
Support	<ul style="list-style-type: none"> • Where do you get support from as you respond to these challenges? Social, statutory, third sector and other sources. 	10 mins	
Research questions – key stakeholders and life story interviews	<ul style="list-style-type: none"> • Discussion of key research questions and topics, to find out more about the priority issues identified, in interviews with: <ul style="list-style-type: none"> • women living with HIV • HIV service providers • Specialist HIV clinicians • Other health professionals • Charity staff • HIV policy makers 	15 mins	
Closing	<ul style="list-style-type: none"> • Reminder of confidentiality and ground rules agreed to • Reminder of next steps in the research project • Signposting to support 	5 mins	<i>Support handout</i>

Appendix 6: University Research Ethics Committee Approval Letter

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Appendix 7: Indicative questions for key stakeholder interviews

- 1) **Introduction:** profession, role, and responsibilities
- 2) **Ageing and HIV:** interviewees will be asked about their insights and experiences around ageing and HIV, whether this is of interest to their colleagues and organisations, and how this manifests itself
- 3) **Women:** interviewees will be asked firstly their understanding and insights into the specific needs of women living with HIV, and then how this links to, is changed or influenced by ageing
- 4) **Challenges:** interviewees will be asked to define challenges in identifying, understanding and meeting the needs of women living with HIV, conceptually and in practice
- 5) **Current activities:** interviewees will be asked how they or their colleagues/organisations are currently acting to meet the needs of older women living with HIV
- 6) **Future actions:** interviewees will be asked to describe actions that could be taken to better meet the needs of women ageing with HIV
- 7) **Research direction:** interviewees will be asked to suggest issues and questions the research should focus on
- 8) **Workshop outputs:** some of the outputs of the participatory workshops will be shared, and interviewees asked to share their responses and comments
- 9) **Any further comments:** before concluding, interviewees will be asked if there is anything more they would like to add

Appendix 8: Support information provided to workshop and life story interview participants

Agencies and contacts for support

If after participating in this research project, you would like to access support, or have experienced any distress, the following contacts are generally available to help.

Helplines

- Positively UK helpline, 020 7713 0444. Open from 10am-4pm, Monday to Friday.
- Sexual Health Line, 0800 567 123 (funded by the Department of Health)
- THT Direct, 0808 802 1221 (run by the UK's largest HIV charity, the Terrence Higgins Trust: www.tht.org.uk).
- Samaritans, 08457 90 90 90. Open 24 hours a day.

Peer support and HIV charities

- Positively UK: contact on 020 7713 0444 or email info@positivelyuk.org
- Naz Project London: 020 8741 1879 or npl@naz.org.uk
- Positive East: call 020 7791 2855 or talktome@positiveeast.org.uk

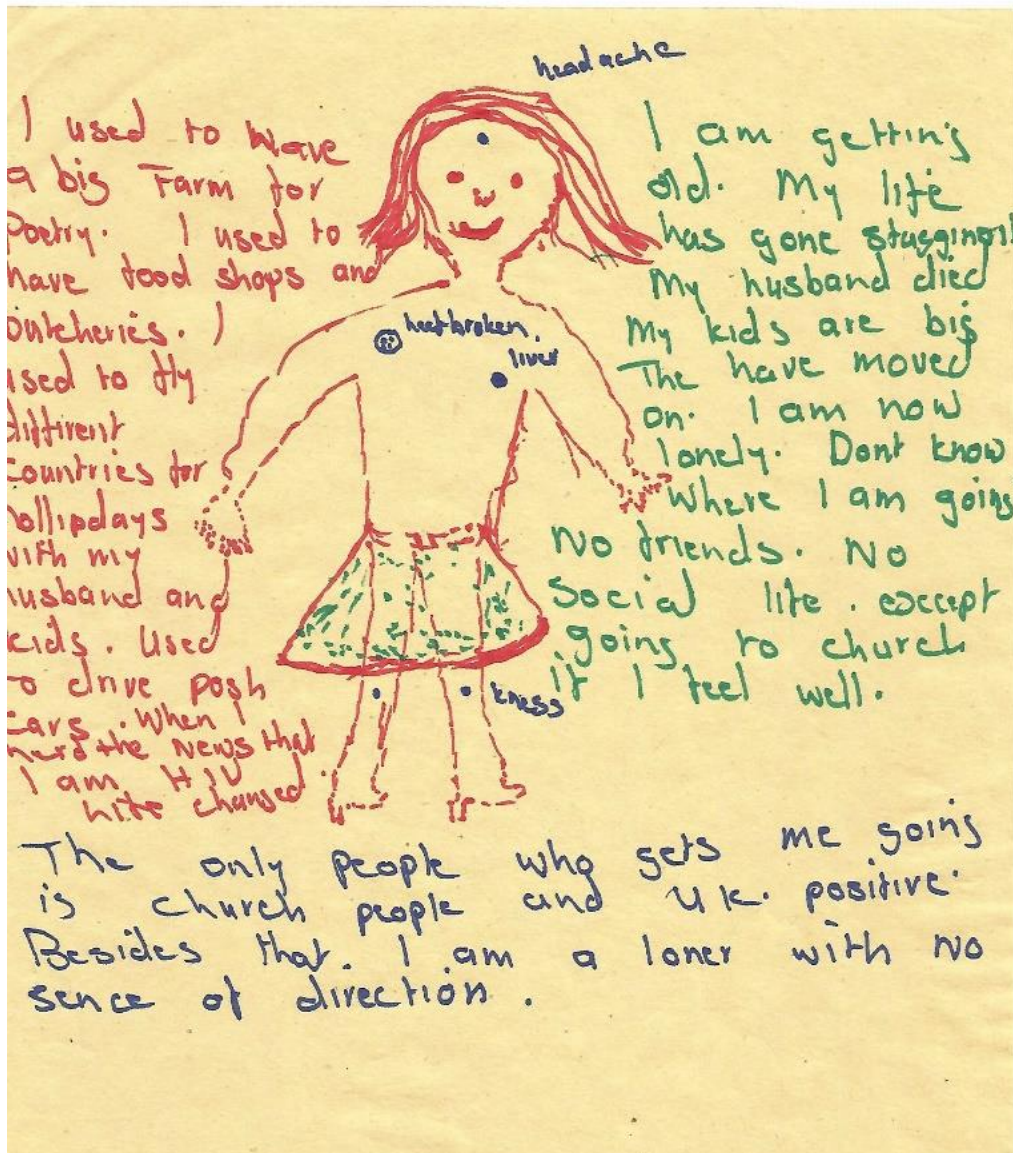
Online support

THT's MyHIV website at www.myhiv.org.uk, provides online peer support

Appendix 9: Body maps and narratives from workshops

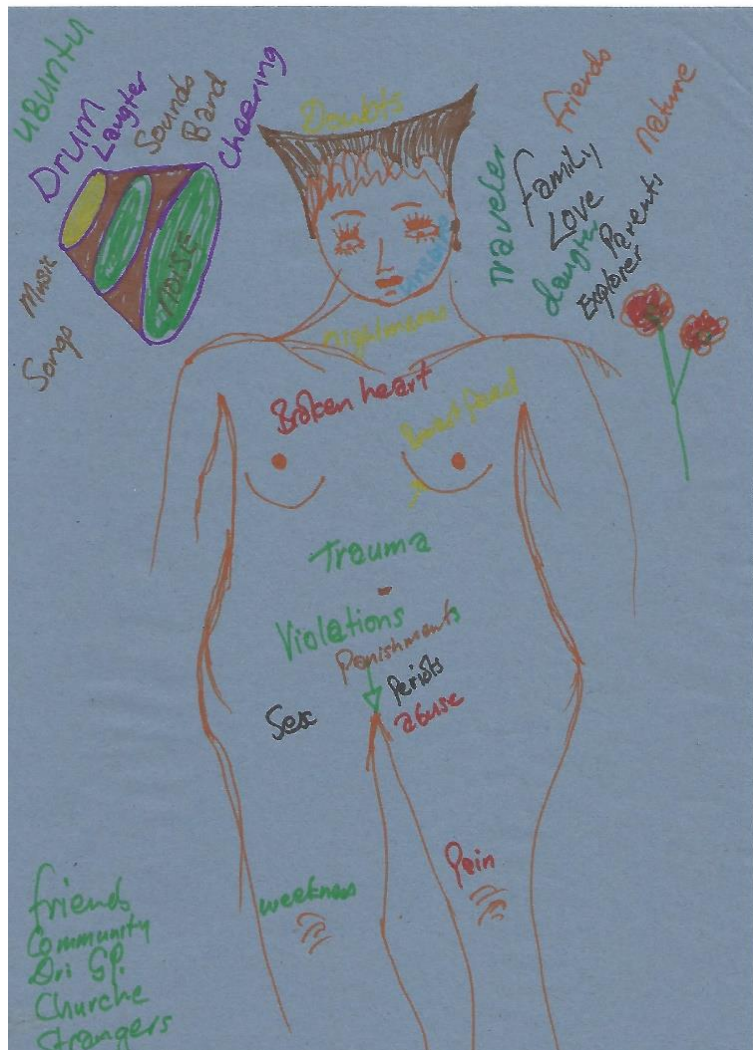
F02: black African woman, aged 50-60, diagnosed for 5-10 years

This is my picture, I used to be a wife, I used to be a mother, I was a business woman at the same time. I did big farm. I used to have food shops and butcheries. I used to fly different places on holidays with my husband and my kids. I used to do everything which a woman would do. But when my husband died that's when I heard the news that I was HIV and my life changed. I am getting my life. My life is gone, strugglement when my husband died. My kids are big and they have moved on. I am now lonely. I don't know where I'm coming from and I don't know where I'm going. No friends, no social life, except going to church where I feel well. And then I've put pictures where I feel pain. My knees, my liver, and I'm heartbroken. And then the last one I wrote the only people who gets me going is church and people from UK Positive. Besides that I'm alone now with no sense of direction.



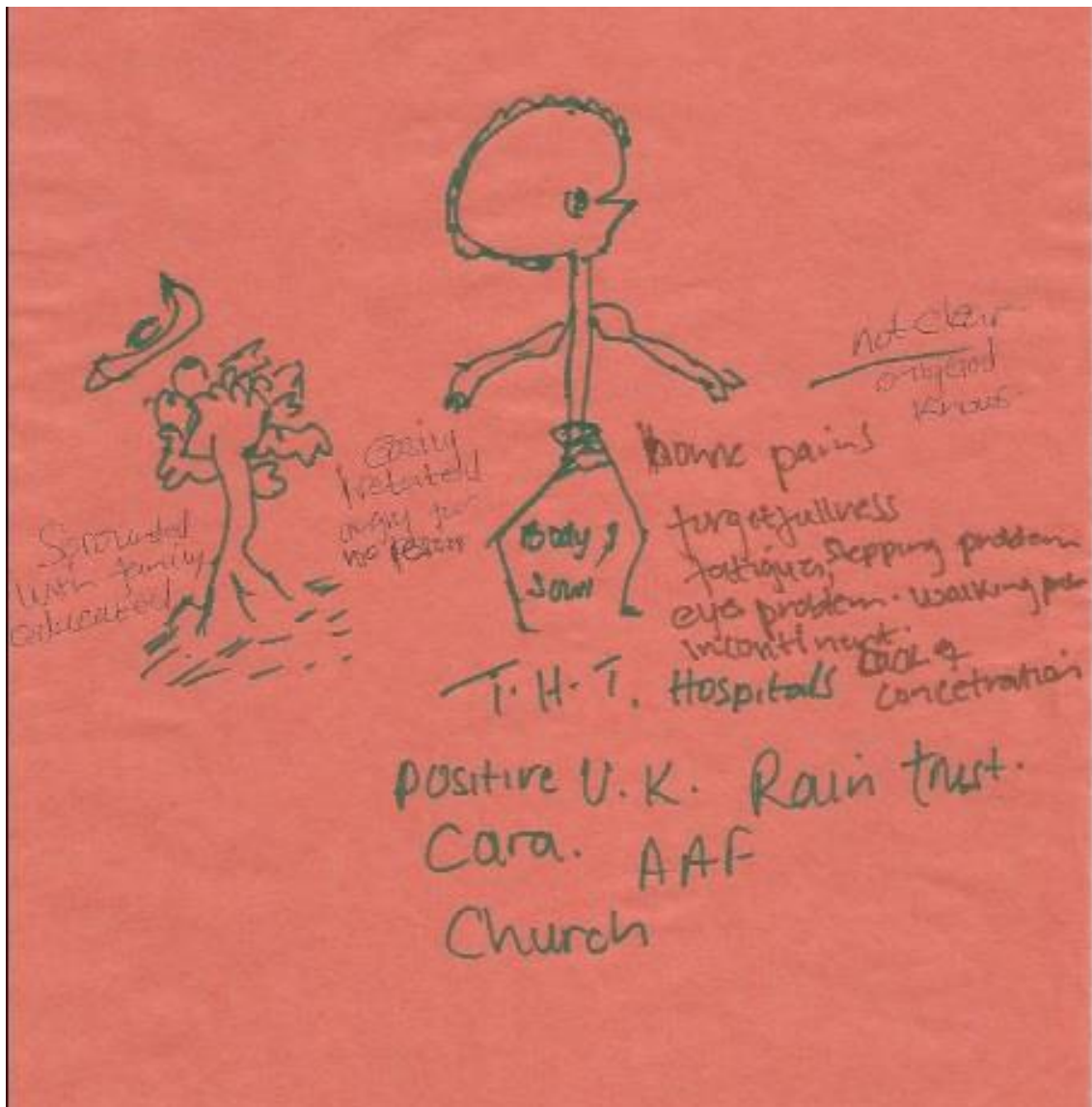
N02 – black African woman, aged 50-60 diagnosed for 10-15 years

On my left side I've put about, I didn't put anything about my childhood because my childhood was a mess so I didn't put much about it. I just put there things about things that kept me going, like Ubuntu. Ubuntu in my country means people, people get together, strangers, you don't even know each other's names but they will be supporting each other and creating Ubuntu, drum or music, laughter, some bands, sharing music and those things kept me, and my energy and supports. And on the support: friends, communities like NAZ and Terrence Higgins, GP, I got a good relationship with my GP, I got a good relationship with my doctors, church community and strangers. Sometimes there are things that I feel easy to talk to strangers about because I know they're not going to know me, I'm not going to meet them again, so strangers is another place where I confront my demons and um. My right side is, travelling, family is the only thing that makes me, keeps me going, exploring, being a parent, and nature, I love nature. And then in my body I put weakness on my knee and the other one pain. And my vagina I put trauma, violations, punishments, periods and abuse, sexual abuse. As a child, because I grew up on the streets so I, I got a lot of those. And my heart's broken. And my breasts, breastfeed, I had to breastfeed, because I was raped and I had to get a child, I had to be a mum and start wearing bras and stuff. And then in my chest I put nightmares, and sometimes I'm scared to go to sleep because they come back to me, and my head - doubts about future, I don't know where my future is.



A01: black African woman, aged 50-60, diagnosed for 15-20 years

Mine is, I came from Africa where I was surrounded with big family, and loved, and well-educated. Then coming here, I got sick, I can't work, I can't do anything. Now growing, getting older, there's no chance of working, as I can see, so. And the future is a bit unclear, I always get lonely, I forget too much, fatigued all the time, lack of circulation, my eyes problem, I can't see properly most of the time, sleeping problem, and I easily get irritated and most of the time I get like angry for no reason. I normally get support from HIV organisations, such as Body and Soul, THT, hospitals, my consultant is good, Positively UK, Rain Trust, CARA, AHPN and my local church but not all the time, sometimes.



Appendix 10: Indicative questions for life story interviews

Taken or adapted from *The Life Story Interview* (Atkinson, 1998).

- How would you describe your early life?
- How would you describe your life now?
- What is the ethnic or cultural background of your parents?
- What cultural values or beliefs were passed on to you?
- What were the most influential events on you in your adult life?
- How would you describe yourself?
- How has HIV shaped or influenced your life?
- Is a sense of community important to you?
- What is different or unique about your community?
- What social pressures have you experienced as an adult?
- What does intimacy mean to you?
- What was it like to turn 30?
 - to turn 40?
 - to turn 60?
- What changes have you undergone since 40?
 - since 50?
 - beyond 50?
- How would you renew your strength, if you felt really drained?
- What values would you not want to compromise?
- Do you feel you are in control of your life?
- What single experience has given you the greatest joy?
- When you think about the future, what makes you feel most uneasy?
- What gives you the most hope?
- Is your life fulfilled yet?
- What would you like to achieve so that your life will seem fulfilled?
- What do you see for yourself in the future?
 - In 5 years?
 - In 15 years?
 - In 25 years?
- What do you want most to experience before you die?

Appendix 11: Analytical framework and table of topics, as revised after participatory analysis workshop

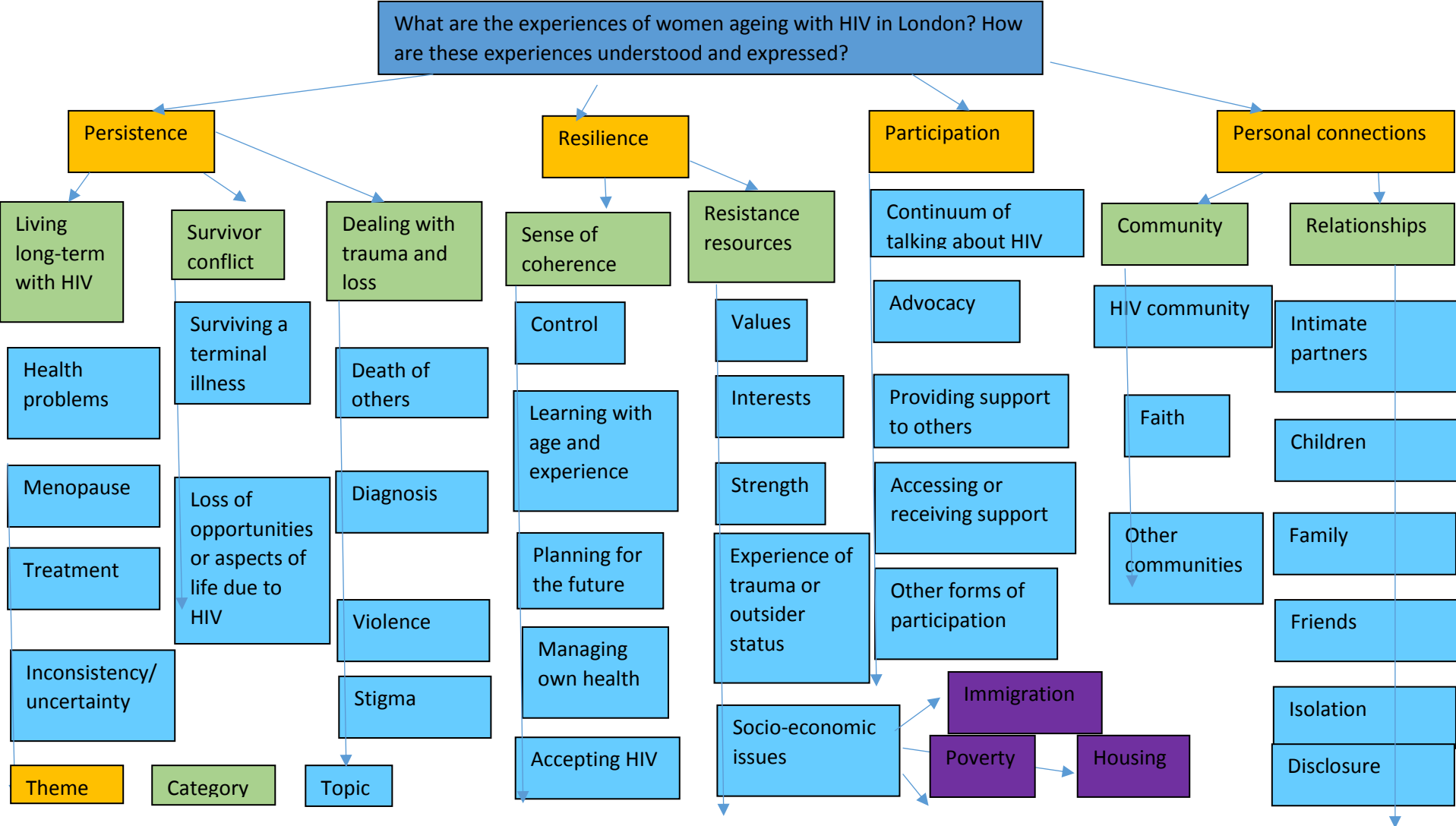


Table of sub-themes

Topic	Sub-theme	Topic	Sub-theme
Health problems	<ul style="list-style-type: none"> • Managing health • Health conditions • Coping with health 	Strength	<ul style="list-style-type: none"> • Finding and building inner strength
Menopause	<ul style="list-style-type: none"> • Worry and concerns • Managing • Moving on from menopause 	Accepting HIV	<ul style="list-style-type: none"> • Ability to accept, a form of healing and control • Unable to accept • Acceptance changing over time/in relation to events
Treatment	<ul style="list-style-type: none"> • Access • Side effects • Relationship with treatment 	Managing own health	<ul style="list-style-type: none"> • Coping by managing own health, being proactive, and looking after yourself.
Uncertainty, inconsistency	<ul style="list-style-type: none"> • Inconsistent symptoms and state of health • Unsure what to attribute to HIV/ageing/medication • Concerns for long-term health • Access to information and support 	Continuum of talking about HIV	<ul style="list-style-type: none"> • From 'necessary lies' to public advocacy, ability to occupy an HIV identity
Death of others	<ul style="list-style-type: none"> • Deaths due to HIV • Traumatic loss • Loss building resilience 	Advocacy	<ul style="list-style-type: none"> • Public disclosure and visibility • Types of advocacy • Motivations for advocacy
Diagnosis	<ul style="list-style-type: none"> • Anger and shock at diagnosis • Impact on life experiences 	Providing support to others	<ul style="list-style-type: none"> • Formal roles in the HIV sector • Informal support through support groups or social networks • Values driving provision of support • Barriers to participating in support • Benefits of providing support
Surviving a terminal illness	<ul style="list-style-type: none"> • Receiving, coping with and moving on from a terminal diagnosis • The 'what now?' challenge 	Other forms of participation	<ul style="list-style-type: none"> • Research • Clinical trials • Activism or supporting others on other, non-HIV issues e.g. LGBT community members.

	<ul style="list-style-type: none"> • Facing experiences that were not expecting to live long enough to deal with 		<ul style="list-style-type: none"> • In countries of origin
Violence	<ul style="list-style-type: none"> • Experiences of violence • Link between violence and HIV 	Accessing or receiving support	<ul style="list-style-type: none"> • Benefits of accessing support • Barriers to accessing support • Changing role over time
Stigma	<ul style="list-style-type: none"> • Barrier to opportunities and social connections • Gendered stigma • Hiding HIV and being visible • Non-stigmatising experiences • Layers of stigma – loneliness 	HIV community	<ul style="list-style-type: none"> • Belonging and understanding • Friendship • Changes over time • Practical support • Emotional support • Challenges
Loss of opportunities or aspects of life due to HIV	<ul style="list-style-type: none"> • Lost opportunities • Changes to life plan or direction • Loss of previous life, social status or acceptance 	Faith	<ul style="list-style-type: none"> • Cultural connection • Loss of faith
Control	<ul style="list-style-type: none"> • Taking control • Prioritising happiness and wellbeing 	Other communities	<ul style="list-style-type: none"> • Different communities women belong to • Tensions or challenge between multiple communities • Comparisons to HIV community
Learning with age and experience	<ul style="list-style-type: none"> • Acquiring learning through age and experience • Reflecting and growing 	Intimate partners	<ul style="list-style-type: none"> • Sex, disclosure and transmission • Priorities in a relationship • Value in good relationships • Relationships as open or closed possibility
Planning for the future	<ul style="list-style-type: none"> • Reaching and reacting to milestones and transitions • Planning for future happiness • Possibilities and opportunities 	Children	<ul style="list-style-type: none"> • Motherhood as important role or identity • Motherhood lost or denied • Caring for children • Rewards and challenges • Choosing and preferring not to have children – recognition of positive choices, invisibility of this status

Values	<ul style="list-style-type: none"> • Purpose • Using fear to grow • Survival • Independence • Work/involvement • Culture and background • Faith 	Family	<ul style="list-style-type: none"> • Connection, grounding and identity • Violence, loss and fragmentation
Interests	<ul style="list-style-type: none"> • Pursuing and cultivating different interests 	Friends	<ul style="list-style-type: none"> • Friends with HIV • Other friends • Connections and support
Experience of trauma, or minority/outsider status	<ul style="list-style-type: none"> • Negative experiences building resilience • Outsider status at diagnosis making it harder to cope or adapt • Ongoing outsider status, loss of social acceptance • HIV is not the worst thing that can happen 	Isolation	<ul style="list-style-type: none"> • Isolation through HIV, barrier to social connections
Socio-economic issues	<ul style="list-style-type: none"> • Housing • Immigration • Poverty 	Disclosure	<ul style="list-style-type: none"> • Indirect or unplanned disclosure – social media • Supportive and negative experiences • Disclosure for a purpose

Appendix 12: Outputs from dissemination event

Plain English Summary:

“I was not meant to be here, and I’m still here”: a feminist, participatory and assets-based exploration of women’s experiences of ageing with HIV in London

This research looked at the experiences of women aged over 50 who are living with HIV. As HIV treatment has improved, more people are getting older with HIV. This can lead to challenges, such as coping with stigma, menopause or other health conditions, but women are also coping and doing well with HIV. To explore both positive and negative experiences, this research looked at the tools, strengths and strategies that people have and use to be able to live well.

The study started by looking at the existing research on ageing, women and HIV, to find out what is already known, and what needed more research. Women living with HIV participated in this process by discussing how the research that has already been done compared to their own experiences.

The approach used focused on research to make change, or to do ‘advocacy’. This model used stories and story-telling to understand women’s experiences of ageing with HIV and to make sure that women were both involved in and shaped the research themselves – so it was done with them rather than being done to them or about them.

To carry out the research, a range of different activities and methods were used. This included a creative activity called body mapping, where women were asked to draw themselves and their experiences to help them tell the story of their experiences with HIV. It also included life story interviews, a conversation with a researcher where women were asked to tell the story of their lives and how HIV had been a part of it.

The researcher also spoke to experts including women living with HIV, advocates, HIV doctors and other researchers, and looked at policy documents, to understand how women’s experiences of ageing with HIV fit within a bigger picture of medical and social support and policy.

The research found three main themes or ideas: persistence, participation and personal connections, and resilience. In this context persistence refers to successfully meeting the specific challenges presented by living with HIV. For some women who were diagnosed with HIV or AIDS before the introduction of effective antiretroviral medication, this included being given a terminal diagnosis (being told that they would die because of HIV) and then surviving. This brought many different emotional and psychological challenges. 'Survivor guilt' is a term frequently used by to describe how people might feel because they did not die but people they knew did. Women described this experience as 'survivor conflict', as they feel no guilt. Belonging to a community of other women with similar experiences of HIV was an important way of sharing and learning the skills need to survive and thrive. Resilience is about coping, and the research found support from other women living with HIV helped women to learn how to manage living with HIV effectively. But challenges like not having immigration status or living in poverty in a time of austerity made it hard for some women to cope.

Overall, the research offers new ideas about how to do research and it also reveals some of the priorities, needs and experiences of older women living with HIV.

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