



# An (un)restricted living: a qualitative exploration of the mental health and well-being of people living with HIV in England

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## ABSTRACT

People living with HIV, who have access to treatment, now have normal life expectancy. However, stigma and discrimination continue to affect health and well-being. We conducted focus groups with people living with HIV ( $n = 37$ ), and key informant interviews ( $n = 20$ ) with clinical and non-clinical workers who support people with HIV between May and November 2023. We aimed to explore the ongoing challenges and concerns faced by people living with HIV in England to inform a new model of person-centred HIV care. Participants discussed living well in relation to: 1) an unrestricted living; 2) emotional sexual health and intimacy well-being; and 3) autonomy of health and healthcare. Aspirations for an unrestricted living revolved around experiencing life in the same way as others, rather than having to compromise a sense of self or negotiate experiences differently due to their HIV status. Participants also shared a desire to live fulfilled sex lives without fear of being stigmatised due to living with HIV, and of feeling deserving of a satisfying sex life and sexual intimacy. There was also a particular anxiety about sharing an HIV status with new sexual partners. Conversations around sex and intimacy needed to be opened up to cover topics including pleasure and sexual wellness. A compromised autonomy of health referred to physical health; for example, the need for daily medication. Autonomy of healthcare referred to the challenges of negotiating an often fragmented and fractured healthcare service. Some shared experiences of discrimination by non-HIV healthcare workers and a requirement to advocate for their needs which is a specific challenge for marginalised groups. Person-centred care, which uses an intersectional approach to delivering HIV care, would respond to the needs and aspirations of people with HIV and their whole self. This offers the potential to address HIV-related stigma which continues to hinder progress.

## 1. Introduction

HIV is now a treatable condition with normal life expectancy (Trickey et al., 2023). People with HIV on successful antiretroviral treatment will have an undetectable viral load meaning the virus is sexually untransmittable (U=U) (Rodger et al., 2019). Therefore, treatment-as-prevention (TasP) offers the potential to improve HIV health and well-being outcomes globally (Bor et al., 2021). Nonetheless, research has shown that awareness of U=U among healthcare providers

remains low in some geographical contexts with reluctance from practitioners to share information on TasP (Bor et al., 2021). People living with HIV also face challenges relating to multimorbidity, stigma and discrimination hindering long-term well-being. A primary focus is now on ensuring people age well with HIV, with a good quality of life 'beyond viral suppression', through person-centred care (Lazarus et al., 2023).

Stigma persistently affects people living with HIV, with minoritised communities also affected by a combination of intersecting factors (All Party Parliamentary Group on HIV/AIDS, 2020). Goffman (2009)

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defined stigma as an ‘attribute that is deeply discrediting’ with Link and Phelan (2001) extending this definition to consider the convergence of four interrelated components. These four components include: 1) the labelling of differences between people; 2) cultural beliefs of ‘undesirable characteristics’ leading to negative stereotypes; 3) categorisation of individuals to “us” and “them”; and 4) the power across social, economic and political spheres to stigmatise (Link and Phelan, 2001). HIV-related stigma impacts HIV prevention and treatment outcomes and is associated with anxiety and depression (Armoon et al., 2022). People with HIV who are diagnosed with depression are 61 % more likely to report HIV-related stigma (OR 1.61; 95 % CI 1.38, 1.83), with higher likelihoods of HIV-related stigma also among those diagnosed with anxiety as well as those reporting suicidal ideation (Armoon et al., 2022). However, social support can act as a protective factor, as can addressing other social determinants of health (Armoon et al., 2022; De Jesus and Williams, 2018). Minoritised people living with HIV may also experience further internalised and anticipatory stigma, for example, men who have sex with men (MSM) and racially minoritised communities (Hedge et al., 2021). The international initiative, fast-track cities, aims for zero HIV stigma and discrimination by 2030 (Joint United Nations Programme on HIV/AIDS, 2014).

The estimated prevalence of diagnosed mental health conditions among people living with HIV is high. The 2022 Positive Voices survey found nearly 40% of participants had been diagnosed with a mental health condition, which is greater than the general population in England (Aghaizu et al., 2023). People living with HIV are at an increased risk of developing severe mental illness (e.g. bipolar disorder) (Gooden et al., 2022). Parity of esteem is a principle for treating mental and physical health equally to reduce health inequalities (Mitchell et al., 2017). There is an assumed bidirectional relationship between HIV and mental health and people with HIV experience a unique set of intersecting vulnerabilities including psychosocial factors (Gooden et al., 2022; Remien et al., 2019). Societal, structural, neighbourhood and individual level factors (e.g. perceived and actual stigma) contribute to poor mental health (Remien et al., 2019). Research indicates that integrating mental health and HIV care can improve outcomes for people with HIV, including reducing symptoms of depression (Conteh et al., 2023).

The Needs Informed model of Care for people living with HIV (NICHE) is a five-year research programme to improve the mental and physical health of people with HIV in the UK (NICHE, 2022). NICHE aims to develop and trial a new person-centred model of care which focuses on routine assessment of psychosocial need through health coaching and social prescribing (NICHE, 2022).

Our research question was: what are the ongoing challenges and concerns for people living with HIV in England? This included an exploration of experiences across various ecological levels including among individuals, family/friends and wider community/society. Our findings from this formative work were then used to inform the intervention design of NICHE.

### 1.1. Theoretical approach

Our study is underpinned by social constructionism and we explored the meanings and interpretations of participants’ ‘constructed realities’ and how these are formed through their social nature (Ormston et al., 2014).

We contextualise our findings using intersectionality (Crenshaw, 1991) and biographical disruption (Bury, 1982). Intersectionality highlights the multiple identities people hold and how these may intersect and be affected by discrimination and experiencing inequities within systems of oppression (Crenshaw, 1991). For people with HIV, multiple identities may also interact with experiences of HIV care as well as navigating life generally. People living with HIV may experience racism, sexism, classism and other forms of discrimination (Krieger, 1999) parallel to HIV-related or intersectional stigma (Logie et al., 2011;

Stangl et al., 2019). Intersecting stigma can apply to other health conditions including mental health, cancer and epilepsy (Stangl et al., 2019).

Biographical disruption was first described by Bury (1982) following interviews with people with rheumatoid arthritis. Bury’s conceptualisation of chronic illness shows the impacts on an individual’s sense of self and has also been applied to people with HIV and people who have had mpox (Alexias et al., 2016; Smith et al., 2024). Specifically, an HIV diagnosis results in internalised stigma, altered life plans and impacts on social relationships that leads to a biographical disruption (Alexias et al., 2016). Newly diagnosed people with HIV may experience dynamic feelings of hope, despair and hopelessness as there is a shift in perceptions of their anticipated life trajectories (Kylma et al., 2001; Wells et al., 2023). However, some people may also experience ‘biographical reinforcement’ whereby an HIV diagnosis brings positive change to their life, for instance, the opportunity for personal growth (Wells et al., 2023).

## 2. Material and methods

Our formative research included focus group discussions (FGDs), with people living with HIV, and key informant interviews with people working in the care and support of people with HIV. FGDs were completed to provide context for two theory of change workshops that informed the NICHE programme’s randomised controlled trial intervention design in September 2023. Interviews were conducted until we had spoken to a diverse range of people according to occupation. Topic guides were piloted and simplified by the team.

Our research team was made up of social scientists, HIV clinical academics and people with lived experience of HIV.

We report our approach and findings according to the consolidated criteria for reporting qualitative research (COREQ) checklist (Tong et al., 2007) (Supplementary File 1).

### 2.1. Focus group discussions

We held FGDs between June and September 2023. FGDs were held in London (n = 5), Yorkshire and the Humber (n = 2), South East (n = 1) and South West England (n = 1). Participants of four of the London FGDs were recruited through a survey emailed to participants of the 2022 Positive Voices survey (Aghaizu et al., 2023) who had provided consent to be contacted about further research. The 2022 Positive Voices survey was completed by 4618 people with HIV (4540 with sufficient demographic details) accessing care across HIV clinics in England (n = 99), Scotland (n = 1) and Wales (n = 1) (Aghaizu et al., 2023). Information about the FGDs and links to a survey to register to participate were also circulated by London-based voluntary sector/community organisations working with people living with HIV and advertised on the NICHE study website (NICHE, 2022). Participants for FGDs were purposively sampled for diversity, including women; people who identify as lesbian, gay, bisexual, transgender, queer, questioning and more (LGBTQ+); people of Black ethnicities; and people aged 60+. Participants were organised into groups with people from similar demographic backgrounds (where possible) to support familiarity. Five FGDs were recruited through participating clinics of the NICHE programme across the different geographical regions detailed above.

We aimed for six to eight participants per group. However, given recruitment challenges, we decided to hold more FGDs with fewer participants. The number of participants in each group ranged between three and seven people, with most groups comprising of three or four. FGDs were facilitated by one or two researchers (LC, FC, TCW, JS) and ran for approximately 90–120 minutes. All FGD participants were given a £40 voucher to recognise their time and contributions.

The FGD topic guide (Supplementary File 2) was organised into two main sections. The first included general discussions exploring what ‘living well’ meant to participants and the different challenges and

concerns that continue to affect people with HIV. The second part looked specifically at the potential design of a new support intervention, exploring participants' views on different components of the intervention, what was felt was needed and how this might work in practice. This paper focuses on data from the first section of group discussions.

## 2.2. Key informant interviews

We also conducted semi-structured, online interviews on Microsoft Teams with key informants involved in the care and support of people living with HIV and delivery of HIV services (e.g. community workers and HIV clinicians). Participants were recruited by convenience and snowball sampling and were identified from HIV organisations (professional and community). Interviews were conducted between May and November 2023 by a female, qualitative researcher (LC) and ran for approximately 40–60 min.

The interview topic guide (Supplementary File 3) followed a similar format to the FGDs. First, we explored views on the challenges and concerns affecting the lives and well-being of people with HIV, followed by an exploration of the potential intervention design.

## 2.3. Data analysis

Participants provided consent to audiorecord FGDs and interviews which were transcribed verbatim by an external company that the University has a confidentiality agreement with.

We conducted a form of rapid analysis of FGDs on account of time constraints of the broader research programme, with different analytical approaches used for the different sections of FGD material. We used a framework approach (Gale et al., 2013) guided by topic guide areas/questions to analyse the FGD data exploring intervention design. An inductive approach (Thomas, 2006) was used for the coding and analysis of sections of FGD transcripts that explore what living well means to people with HIV, which forms the focus of this paper. This involved initial coding of transcript data that was iteratively developed and refined through reading within and across the different group transcripts by LC. Analytical notes exploring conceptual areas of the data – how these resonated and/or diverged across participant and group narratives – were written in conjunction with the inductive coding. Initial coding and analysis were then developed and refined in group discussions with members of the research team (LC, CW, AS, CM, FB) and worked up into the three interconnected core narratives of the analytical frame presented below. These themes were not pre-determined by the research team.

Broader theoretical contextualisation of the findings exploring resonances with intersectionality, as well as the narrative threads of the harms of social isolation and 'eroding of self' (or biographical disruption) were later developed by VP in collaboration with members of the research team. The findings of this paper present the analysis of FGDs with some data presented from interviews that align with focus group discussion topics.

## 2.4. Ethical approval

All participants provided informed consent to participate. Ethical approval was provided by the Health Research Authority (REC ref: 23/IEC08/0008).

## 3. Results

37 people living with HIV attended nine FGDs. Participants represented a diverse range of ages, genders, sexualities and ethnicities. A summary of the characteristics of FGD participants can be found in Table 1.

We also conducted interviews with 20 key informants involved in the care and support of people living with HIV and/or design or

**Table 1**

Summary characteristics of focus group participants.

Characteristic	Focus group participants (N = 37) n (%)
Age	
18–34	5 (13.5)
35–44	4 (10.8)
45–54	8 (21.6)
55–64	16 (43.2)
65+	4 (10.8)
Gender	
Cisgender woman	11 (29.7)
Cisgender man	23 (62.2)
Non-binary	2 (5.4)
Non-binary transgender	1 (2.7)
Ethnicity	
White British	13 (35.1)
White Other (including US, European, Eastern European)	8 (21.6)
Black African	8 (21.6)
Black Other (including Black British, Black British-African, Black Caribbean)	4 (10.8)
Mixed/multiple ethnicities	3 (8.1)
Other ethnicities	1 (2.7)
Year of diagnosis	
1982–1995	7 (18.9)
1996–2005	13 (35.1)
2006–2015	13 (35.1)
2016–2021	4 (10.8)
Sexuality	
Gay or lesbian/homosexual	18 (48.6)
Heterosexual/straight	12 (32.4)
Bisexual	4 (10.8)
Queer	2 (5.4)
Asexual	1 (2.7)
Country of birth	
Born in UK	20 (54.1)
Not born in UK	17 (45.9)

commissioning of services. This included charity and community-based organisations (n = 9) and HIV clinics (n = 11). Roles ranged from clinical (e.g. HIV consultants and specialist nurses) to community roles (e.g. support workers and welfare advisors). Key informants were based across England including London (n = 9), South East England (n = 5), North West England (n = 3) and national organisations (n = 3).

We identified three interconnected core narratives in FGDs on living well: 1) an unrestricted living; 2) emotional sexual health and intimacy well-being; and 3) autonomy of health and healthcare. These shared narratives were underpinned by pervasive and persistent HIV-related stigma and a sense of erosion of self. A summary of the themes and how these relate to the underlying theory can be found in Fig. 1.

### 3.1. An (un)restricted living

Living well was discussed regarding practices of living in an 'unrestricted' way. Despite improved therapeutic innovation in HIV, participants shared feeling constrained in small but pervasive ways. Participants spoke to aspirations of, and limits to, an 'unrestricted living.' They reflected on the ongoing and relentless need to negotiate their lives differently, of having to think about things that other people do not have to or make decisions due to living with HIV in a way that others do not.

*... it's about living unrestricted compared to those who are not HIV positive [...] every now and then there is something small that crops up [...] But it always brings back that feeling [...] where you think, 'oh yes, I am different because of that, and I need to change my behaviour and not do certain activities and things.'*

[cisgender man, white British, gay/homosexual, 18–34 years old (diagnosed 10+ years)]

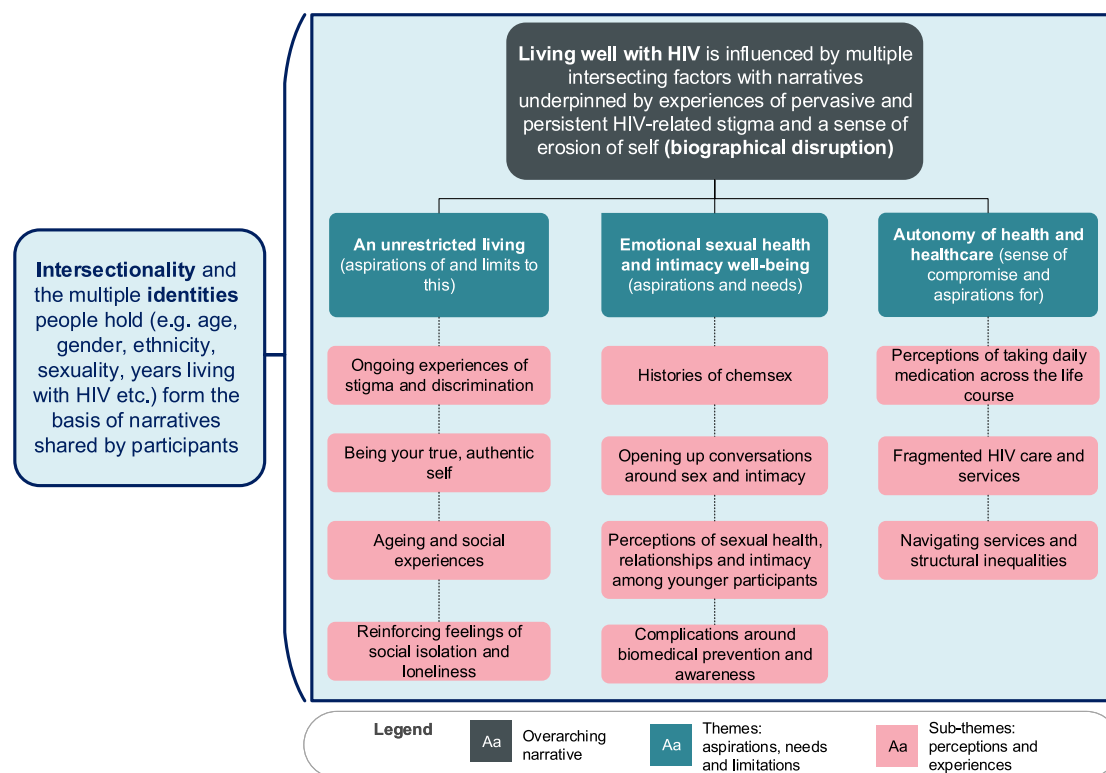


Fig. 1. Overarching narrative, themes and sub-themes identified.

### 3.1.1. Ongoing experiences of stigma and discrimination

Participants described repeated instances of discrimination due to their HIV status where they were treated as, and made to feel, different. This included everyday interactions and experiences that set them apart and position them as ‘other’. Some examples given included negotiating unaffordable travel insurance premiums, the restrictions some countries have on entering with HIV medications and being refused services at tattoo studios and beauty salons.

... there are all these weird invasions of what feels like should be your privacy and stuff that you have to just deal with, people in your shit. You can't just go somewhere and live [...] You have to take the pills with you and they're scanning your suitcase ...

[cisgender man, black British-African, straight/heterosexual, 18–34 years old (born with HIV)]

Ongoing experiences of discrimination have become embedded with feelings of otherness resulting in internalised stigma. Participants felt they must negotiate the world differently which introduces additional limitations to their lives. As observed by a key informant, this can include a hesitancy to advocate for needs.

... what I've witnessed is that for most people it's the stigma. It might be internalised stigma, but it might be stigma coming from the community or service providers, or from past bad experience. They tend not to want to force, [...] assert their rights, demand what's right [...] for example, taking time off from work to go to attend appointments ...

[Welfare Advisor at national charity]

### 3.1.2. Being your true, authentic self

Participants also shared experiences of ongoing navigation of social misconceptions and ignorance. This materialised through feeling unable to be their true, authentic selves in social and relational networks. Having to be selective and careful about the information they share,

when and with whom, left participants feeling lonely and isolated. They spoke of the ongoing need and emotional strain of having to live a ‘split’ or ‘double’ life (i.e. a sense of biographical disruption); a part where their HIV is known, lived, and moved with openly and a part where it remains carefully negotiated and managed.

... there is this self-inflicted stigma of having to exist with this illness and not be able to be open about it. For all the reasons where you fear your colleagues, your family are going to ostracise you, are going to judge you [...] and I think that contributes to mental health issues. To loneliness, isolation. Never permitted to be honest open about it, living a lie almost, a split personality of some sort where you have to almost act as being somebody else in one place, in family settings ...

[cisgender woman, white Eastern European, bisexual, 45–54 years old (diagnosed 20+ years)]

Discussions around living well centred around the importance of feeling part of a community but critically one ‘where you can be your full self.’ Talk of this aspiration and need were challenged by how difficult, and at times unimaginable, this can be outside the safety of specific networks and spaces.

I had a few friends at the beginning [when diagnosed with HIV] so I had a support network [...] but slowly, over time, as the reality of disclosing and that potential for rejection became harder and harder for me [...] Stigma is a huge thing.

[cisgender man, white British, gay/homosexual, 45–54 years old (diagnosed 15+ years)]

### 3.1.3. Ageing and social experiences

For one young adult, restricted living is experienced by not being able to live life in the same way as their peers (e.g. the perception that the ‘crazy years at University’ is something not available to them). They must negotiate different parameters and constraints which their peers do



not have to contend with.

*... the idea of relationships and how my next steps of life are and how I see my friends navigating through the world in a way that I can't navigate [...] Having the crazy years at university [...] is something I'm very aware I can't have or [...] if I was in a relationship, I'd have to disclose to someone about this thing and, in their head, they would feel very right to stigmatise me for it. I could be shunned or belittled or hated because of something that I can't change.*

[non-binary, black African, queer, 18–34 years old (born with HIV)]

They also shared feelings of shame or guilt for wanting to experience these social experiences as others do.

*... now I'm dirty and unclean for wanting to engage in the world in the same way that everyone else gets to do. That's a really big one for me when I found out and knowing that since I was a child, and you almost get a section of your life cut off quickly. You get a level of cold reality too soon that other people don't necessarily have to grapple with themselves.*

[non-binary, black African, queer, 18–34 years old (born with HIV)]

### 3.1.4. Reinforcing feelings of social isolation and loneliness

Participants shared how living in a 'restricted' way, with parts of their lives hidden, makes connections with others difficult and can reinforce and intensify feelings of isolation and loneliness. There is an additional concern of the anticipated emotional burden that sharing your status could impose on others, which is balanced alongside a sense of questioned legitimacy given that society no longer considers HIV to be a public health concern. No longer the emergency or crisis it once was, there is less time and space for HIV in public consciousness.

*That isolation becomes compounded and there's all this secrecy and you've really got to measure who you include in your circle and who you trust and why you're telling them and all the psychology of burdening them [...] I write stories about vampires and stuff because they live in secret because that's how I feel [...] There are LGBTQ people, but I feel like we're another group that is silent because people are like, 'HIV ended in the '90s and 2000s.' It's not an epidemic anymore so we don't talk about it, or we don't think about it.*

[cisgender man, black British-African, straight/heterosexual, 18–34 years old (born with HIV)]

Decisions to 'hide' within communities can also restrict access to services or support groups.

*Black African women are the biggest group of HIV positive people in this area, so there is much more stigma, perhaps, involved about coming to our group that they might not want to be seen by people in their community.*

[Patient Representative, London HIV clinic]

Participant accounts collectively reflected the emotional wearing and fatigue of this 'performance of living,' an ongoing erosion (or biographical disruption) that make 'a normal life' inaccessible.

*... having this performance of living a different life and not being able to be authentic, that is the thing that I think people really underestimate [...] it's just always eroding at your life. It just means that you can't have a normal life.*

[cisgender woman, white British, bisexual, 55–64 years old (diagnosed 20+ years)]

## 3.2. Emotional sexual health and intimacy well-being

Participants reflected on an aspiration and need for positive sexual health, intimacy, and well-being. This materialised in different ways for different people but centred around sexual health that was more than just 'safe sex.' Participants referred to sexual health that considered, and attended to, broader emotional needs and desires for both sex and

intimacy with others.

### 3.2.1. Histories of chemsex

For some participants, sexual health was entangled with histories of chemsex [intentional sex whilst using psychoactive drugs (McCall et al., 2015)], the process of transitioning out of social networks and community, and establishing new forms of sexual intimacy and relationships.

*how can I incorporate sex back into my life? It's not necessarily about being HIV positive but the whole [...] picture involves it in one way or the other. And I think for people who aren't in a relationship, and you are having to disclose your status and all the rest of it. So, I think sex is, attitudes around sex, and not safe sex in that sense, but [...] healthy sex lives and how to [...] navigate that.*

[cisgender man, white US, gay/homosexual, 45–54 years old, (diagnosed 10+ years)]

While one participant alluded to a 'loneliness' of chemsex experiences, another reflected on the difficulties of 'incorporating sex back into [your] life.' Finding and navigating different forms of sexual relations and community highlights how living with HIV and associated forms of isolation and exclusion, can unfold and be experienced in new ways.

### 3.2.2. Opening up conversations around sex and intimacy

FGD participants discussed aspirations toward a 'healthy' sex life, where health extends beyond the prevention of either acquiring or passing on a sexually transmitted infection to focusing on pleasure and intimacy. Women over 45 felt that conversations on sexual health needed to move beyond clinical parameters and priorities, to broader considerations of healthy sexual experiences and relations. Participants discussed how women in their 40s and 50s living with HIV need to feel deserving of sexual intimacy and pleasure.

*... I definitely feel like a lot of them [older black women living with HIV] stop thinking about romance and partners in a realistic way because of their status, and I find that really sad. Because it's just like they're amazing, beautiful, really funny people, and yes, they are also deserving of that kind of love and that kind of attention. But I think they also do it to themselves, but it's also society who's also telling them that they are no longer deserving ...*

[Sexual Health Community Advice/Support Worker]

FGD participants collectively reflected on the need for, and importance of, women with HIV in their 40s and 50s to feel that positive sexual experiences and intimate relationships can be a part of their lives, and more critically, something they are allowed to want for themselves. This was closely interwoven with narratives around self-worth and the often-compromised belief of being deserving of a good quality of living.

*... the amount of women who just put up with not having any sex life because they just don't think it's available to them, and it just takes that one person to question them and say 'why not?' [...] So, there is an opportunity for some empowerment [...] it's that opportunity just to ask a bit more than what's your viral load, what's your weight, what's happening?*

[cisgender woman, white British, bisexual, 55–64 years old (diagnosed 20+ years)]

### 3.2.3. Perceptions of sexual health, relationships, and intimacy among younger participants

Concerns related to intimacy and sexual wellness were also present among younger participants who discussed an acute anxiety their HIV status provoked in negotiating and navigating intimate relationships. Participants spoke of the challenges of navigating new relationships, of when to share their status and the added layer of trust needed to do this.

*I think that [living with HIV] makes it very hard to step into having relationships. You've got another extra layer of trust that you've got to build*

off, “Can I tell this person this thing about me? Will they hate me because of it? If they do, will they tell someone else about it?” Whereas I feel like trust is so simple for people who are negative [...] but will you betray me in a way that I and society feels is justified?

[non-binary, black African, queer, 18–34 years old (born with HIV)]

Participants shared a persistent concern for the possible reactions that sharing their status might elicit. This feeling was perpetuated by discrimination that persists in society which has led to an internalised belief in the fairness of this rejection and perception of love being ‘conditional.’

P2: I should be able to believe the words, “I love you” or “I care for you” are just that but I know that’s not true for me and for being positive because I love you has been said, I’ve told them my status and they don’t love me anymore. How can that be true? How can both of those be true? I know any love that I receive is conditional.

[P2: non-binary, black African, queer, 18–34 years old (born with HIV)]

P1: There’s an ‘if’ after it.

[P1: cisgender man, black British-African, straight/heterosexual, 18–34 years old (born with HIV)]

### 3.2.4. Complications around biomedical prevention and awareness

Some MSM participants discussed the impact of pre-exposure prophylaxis (PrEP) on navigating sexual encounters and relations. One participant discussed how he felt that PrEP, and subsequent dating app classifications that delimit those on PrEP and those not, had displaced broader understandings around HIV transmission (U=U). This included misconceptions and an absence of knowledge that an undetectable viral load provides the same level of protection as being ‘on PrEP.’ In fact, U=U provides higher protection than PrEP (Centers for Disease Control Prevention, 2020).

he saw me take medication once and he asked [...] was it PrEP? And I said yes, and then like a few weeks later I said it wasn’t actually PrEP that I was taking – but it’s always that you are forced into the position where you have to lie, well you don’t have to ...

[cisgender man, white British, gay/homosexual, 18–34 years old (diagnosed 10+ years)]

### 3.3. Autonomy of health and healthcare

Group discussions also explored a sense of compromised autonomy and aspirations toward an autonomy of personal health and healthcare. Constraints to autonomy of physical health were experienced in different ways according to the age of participants and the respective point of the treatment-trajectory they were navigating and negotiating. Limits to autonomy were also discussed in relation to experiences of health services and interactions with health professionals.

#### 3.3.1. Perceptions of taking daily medication across the life course

For younger adults, we found that limits to an autonomy of health related to having to take daily antiretroviral medications. They referred to the ongoing need for treatment and the simultaneous anxiety of something going wrong. Young adult participants discussed a sense of ‘not having a say’ in their health and having to think about the potential implications of decisions and actions to their health in ways their peers do not.

P2: ... I don’t get to have a say in my health [...] I have to take my meds every single day no matter how sad I am, how angry I am, how frustrated I am about my health. [...] it took me a very long time to accept that I had to take medication. I was keeping up on my health, eating well and exercising every single day for four hours a day to stop myself from taking medication and it didn’t matter. I still had to take medication and that doesn’t seem, I hate to use this word, fair because other people get to

navigate the world normally, right? That idea of I don’t have any control over my health, and I know taking meds is a level of control over my health but only to a certain extent. I could go into hospital the next day and they tell me my CD4 count is bad, but I’ve done nothing different.

[P2: non-binary, black African, queer, 18–34 years old (born with HIV)]

P1: The medicine could just stop working.

[P1: cisgender man, black British-African, straight/heterosexual, 18–34 years old (born with HIV)]

Some participants had been taking antiretroviral medications for decades. Their concerns focused on the potential impacts of earlier treatment regimens on their bodies and the lack of knowledge about the effects of lengthier treatment trajectories. Several references were made to being the ‘first generation’ of people to age with HIV and the absence of knowledge and continued unknowns that surround this. These concerns included how previous treatment regimens had already impacted their bodies and how future co-morbidities could be affected by, and affect, their HIV medications.

Several participants also referred to having been diagnosed before effective treatment was available, when people were dying from AIDS-related illness. Experiences of bereavement, coupled with trauma from the loss of close friends and partners, saw narratives of therapeutic concern simultaneously often countered with narratives of gratitude.

I think some of our older patients have got quite a lot of trauma [...] of initially being diagnosed, and feeling that [...] was a death sentence, and some survivor’s guilt, and watched loved ones die.

[Nurse Manager, South East of England]

Women living with HIV who were in their late 40s and 50s also spoke about a sense of compromised health autonomy due to a lack of understanding of changes to their bodies with menopause and physiological shifts that are not due to living with HIV. Women wanted to better understand their bodies and to what extent physiological changes are related to, or impacted by, their HIV status.

P2: ... naming it means that you feel a bit more in control [...] these night sweats are because, this is natural, this is normal for a woman of my age, this is what happens, and so therefore – I feel out of control, but I feel in control of being out of control, if that makes sense?

[P2: cisgender woman, white British, bisexual, 55–64 years old (diagnosed 20+ years)]

P1: It’s knowing why you are out of control.

[P1: cisgender woman, black Caribbean, straight/heterosexual, 55–64 years old (diagnosed 15+ years)]

#### 3.3.2. Fragmented HIV care and services

Constraints to autonomy were also experienced and discussed in relation to access to health services and interactions with practitioners. Participants shared the difficulties encountered and resources needed to navigate a fragmented and failing care system, including a perceived detrimental impact from the shift of specialised clinics to primary care. This included perceptions that general practitioners (GPs) were less receptive to a holistic approach to care, with a more limited understanding of whether health concerns may or may not be related to HIV. Participants were less trusting of GP services, and felt GPs were at times working from limited or incomplete information.

We wouldn’t expect the GP to know everything, but it would be good if they were actually admitting that they don’t [...] it’s almost like a trial and fail but still I think we want them to make an effort and actually listen to you.

[cisgender woman, white Eastern European, bisexual, 45–54 years old (diagnosed 20+ years)]

Participants spoke of being tired of the back-and-forth between the HIV clinic and GP given the poor service infrastructure and seemingly

absent coordination between them. One participant also shared challenges with navigating multiple services and appointments.

*That [multiple separate appointments] can be very demanding in terms of your memory and your ability to write down all the appointments because you end up with so many [...] in so many different places, it just becomes a muddled experience. You have to work out and you have to do a diary [...] Sometimes, on the same day, you have two appointments, and you have to travel to [hospital name], [area] and that affects your budget as well because you're having to pay for all these things.*

[cisgender man, other ethnic group, straight/heterosexual, 55–64 years old (diagnosed 20+ years)]

One HIV clinician who was interviewed emphasised the role HIV clinics had performed in siloing – albeit for protective purposes (of their own HIV services and people with HIV attending services) – those living with HIV from other healthcare services and practice. They discussed how emergent concerns are less unique to people living with HIV but issues that can and do disproportionately affect HIV populations.

*... there's a degree to which people with HIV, thanks to the success of treatment, are freed up to deal with all the joy and all the crap that life throws at you as well. So, there are some overarching issues that even if they are overrepresented amongst people living with HIV are far from unique for people living with HIV [...] I largely think the future should be based on us better integrating people with HIV across broader health and social care sector [...] we [HIV services] have been overly protective of our services for too long, and we have been barriers to integration for far too long. What we do about that when primary care is falling apart, I don't know [...] but I think we missed opportunities to start working towards this 10/15 years ago.*

[HIV Consultant Clinician, London-based clinic 1]

Another clinician interviewed highlighted the need to negotiate the 'balance' of the HIV treatment revolution and for specialist approaches to clinical care that GPs are not able, or supported, to provide.

*... wanting to tell people that their life expectancy is normal, that if they take brilliant antiretroviral therapy that everything will be great, whilst also continuing to have data reported that shows that people are more at risk of certain conditions [...] 'How do you match this thing that you keep telling me it's normal and that I've got a brilliant life expectancy and I should not worry about it, whilst also every now and again updating me on new data sets that tell me I should take a statin when if I didn't have HIV I shouldn't' [...] But actually if we're to continue to really look out for those things that we know occur with heightened prevalence in people with HIV, we need to keep that in specialist services.*

[HIV Consultant Clinician, London-based clinic 2]

This was a tension of approach and delivery experienced and shared as a concern by a participant with HIV who recalled they felt frustrated when clinic staff, whilst trying to reassure and alleviate anxiety, failed to provide them with the information they were looking for.

*... I kind of worry about the whole lifespan thing [...] doctors and everybody else minimise it so much. And I appreciate that, at the clinic, they're not trying to scare you and stuff, and they want to give you hope – "There's no cure. There is a way you can cope with it." But sometimes, I don't want to be coddled and told it will get better, I want you to give me actual facts. [...] Once you get off the phone or I leave, your life is continuing just like it is. You're minimising what's happening to me or what could happen to me, that doesn't help me in the long run. [...] Because, if I was going to be better, you wouldn't care about my viral load. You're checking it over and over again, every few months, for a reason, because you don't want me to get there [detectable viral load].*

[cisgender woman, black African, gay/homosexual, 18–34 years old (diagnosed 15+ years)]

### 3.3.3. Navigating services and structural inequalities

FGD and interview participants both reflected on the different means and resources available to people living with HIV to negotiate structural inequalities. People already struggling with elevated levels of uncertainty and often complex needs must make significant efforts to navigate health and social care systems. For example, people with uncertain citizenship status and people facing systemic racialised injustices and harm face significant challenges navigating the demands of health and social care systems. This can result in a reliance on other forms of social and community support to advocate for resources and needs.

*... white middle-class [...] communities they know how to navigate the system. They know their rights. They know how to articulate for themselves. They know how to get what it is they feel they need. There are some cases again where there is overlap. They also have trauma involved in terms of their diagnosis. They have not told anyone. The stigma, both internal and external stigma, and that affects how they engage again with services. But I think when I look at the two sides [...] the quality of life of a white British is a lot better than [...] of predominant migrant Black Africans.*

[Health and Well-being Support Worker for diaspora communities]

Several women living with HIV also reflected on how the limits of the system work to restrict autonomy in how care services are, and can be, engaged with. They argued that having the self-confidence to advocate for what you need and being assertive when these needs were dismissed or unmet, was fundamental. This included disrupting power dynamics with healthcare professionals to get your needs voiced, heard, understood, and met.

*... getting to a place where you can self-advocate and you are aware of what you want and the services you need. I think getting to that age and knowing that I can go to my GP and say no [...] learn how to say no because I didn't know how to say, I just used to kind of [P1: take what they say] take whatever, you know, and going to these groups and getting empowered and peer support has brought me to the place where I question them and ask questions [...] So self-advocacy is key to well-being ...*

[cisgender woman, black African, straight/heterosexual, 45–54 years old (diagnosed 25+ years)]

FGD participants also shared pervasive experiences of discrimination from non-HIV healthcare professionals recalling both a lack of knowledge and awareness, and at times explicit discrimination in interactions with healthcare professionals and services. They shared feelings of frustration and fatigue at still having to educate others. This was felt more acutely with those who were expected to be better informed.

*P6: Stigma does affect us both internally [...] and the stigma that we get from healthcare professionals. That's probably the worst. In a place where you expect to feel safe and understood you get treated different by dentists or by others, even hairdressers or ear piercers or whoever. [P5: Even GPs].*

[P6: cisgender man, white, gay/homosexual, 45–54 years old (diagnosed 30+ years); P5: cisgender man, mixed ethnicity, bisexual, 55–64 years old (diagnosed 35+ years)]

## 4. Discussion

### 4.1. Key findings

Participants' discussions explored living well in relation to an (un) restricted living; positive sexual health, wellness, and intimacy; and an aspired sense of autonomy of health and healthcare. Underpinning these experiences were the negative and pervasive effects of continued discrimination and societal misconceptions, and an emotional fatigue and sense of erosion of self and life. Stigma is internalised (self-stigma) and people with HIV may experience shame (Bennett et al., 2016; Earnshaw and Chaudoir, 2009). Our findings suggest that different



forms of stigma interact with social isolation, multiple identities and lead to negotiating biographical erosion and repair over time. The multiple identities people hold (e.g. age, gender, ethnicity) alongside their relative power, privilege and other structural forces [intersectionality (Crenshaw, 1991)] form the basis of narratives shared by participants who often referred to their identities to explain why they felt they experienced life in a particular way.

Biographical disruption and repair are demonstrated through our data and communities involved, and has previously been described to carry connotations relating to age, class, gender and ethnicity (Campbell, 2021; Williams, 2000). Specifically, biographical disruption emerges among younger participants (e.g. unable to experience life events like their peers), but also among older gay men who experienced losses and bereavements at the start of the HIV epidemic. For women living with HIV, this is described in relation to forming new sexual relationships, a need for discussion around intimacy and desire, and a lack of clarity around the long-term effects of HIV in the ageing process (e.g. menopause). As people continue to age with HIV and build new relationships and networks, this can result in repairs to these biographical erosions which first emerge at the point of diagnosis and other significant life events including stigmatising experiences. These experiences may be reframed as an opportunity for personal and emotional growth once people are supported adapt to living with HIV such as a sense of strength and empowerment (Hollingsworth et al., 2022; Wells et al., 2023). In essence, some people experience ‘biographical reinforcement’ or a positive transformation in how they view themselves although this may not be experienced by everyone (Tsarenko and Polonsky, 2011; Wells et al., 2023).

Although biomedical advances in treatment have transformed the physiological experiences of living with HIV, this has not been followed by transformations in social relations and practices. Several participants spoke of how living with HIV is shaped by interactions and relations with others, with issues relating to stigma prevalent across multiple communities which intersect with systems of privilege, power and oppression: in other words, intersectionality (Crenshaw, 1991). Ignorance and lack of awareness and understanding of developments in HIV (e.g. U=U) amongst family, friends, work colleagues and sexual partners, alters their way of living as their true, authentic selves. These experiences sometimes also extend to healthcare professionals. For younger participants, this results in feeling excluded from the life events and experiences of their peers. Participants shared feelings of having to hide part of themselves in some areas and spaces of their lives and feeling that they were living a ‘split life’, intensifying experiences of loneliness and social isolation. Stigma is central to living with HIV and experienced across the life course; this differs from pathogens such as mpox and other sexually transmitted infections where although it can be very intense and distressing, stigma generally resolves with recovery (Lichtenstein et al., 2005; Witzel et al., 2024). Approaches to support people with HIV must grapple with the changing impacts of stigma at various life stages.

Participants spoke of aspirations and a need for positive sexual experiences which are emotionally safe and include a sense of sexual wellness and intimacy well-being – to move beyond current parameters of ‘safe sex’. Heightened anxieties exist around negotiating sex with new partners including fears of rejection when sharing a HIV status. Theoretical models of anxiety for sharing a HIV status have suggested internalised HIV stigma is a distal determinant and is also influenced by physiological, behavioural and cognitive factors (Evangelini and Wroe, 2017). A distal determinant refers to a “fundamental or root cause of health” or upstream factor although critics argue that this term conflates concepts related to causality, specifically space, time, level and strength (Best et al., 2021; Krieger, 2008). Stigma results in participants struggling with their sense of self-worth, confidence, and deservedness for positive and pleasurable sexual experiences. Some viewed love and intimacy as conditional experiences. Additionally, biomedical advances are negotiated through socio-political dynamics that can see inequalities

remade in new ways (Bernays et al., 2021), as reflected here in how the prevalence of PrEP discourses among sexual partners and networks feel to be overshadowing knowledge and understandings of the significant affordances of U=U.

The third area identified relates to autonomy of health and healthcare and how constraints of these were experienced over time. Younger participants associated this with taking daily medications and for some, an underlying anxiety that antiretrovirals may stop working. Older participants, with more extensive treatment trajectories, shared the unknowns of the longevity of side effects related to current and previous HIV therapies. This has previously been described as an ‘embodied experience’ by Alexias et al. (2016) who also found evidence of changes to body image. Participants shared a need to understand whether bodily changes (e.g. the menopause) are, or are not, related to or affected by their HIV status or medications, as highlighted in previous research (Tariq on behalf of the PRIME Study Group, 2018). Participants described challenges in access to health services, instances of negative experiences and interactions with non-HIV healthcare professionals, and the resources and confidence needed to self-advocate and navigate the demands of increasingly fragmented services. For example, multiple appointments at different times and in various locations, alongside a back-and-forth between HIV clinics and GP practices, together with ineffective communication and co-ordination within and across services. Issues around fragmented services are highlighted in wider literature (Catalan et al., 2020). Both people living with HIV and practitioners shared a perceived concern for people and communities who have inequitable means and resources to negotiate pervasive institutionalised inequalities. These inequalities are found at intersections of socioeconomic disadvantage, racialised and gendered violence, precarious citizenship status and rights, homophobia, and multiple health concerns and co-morbidities.

#### 4.2. Strengths and limitations

Our formative work used a combination of qualitative methods to record the challenges faced by people with HIV. These provide helpful insights to support the development of the NICHE programme of research. Participants represented a range of backgrounds; however, most were men over the age of 45 who identified as gay/homosexual and white British. Participants also included heterosexual women, people of Black ethnicities and those of older and younger age groups, reflecting the epidemiology of people living with HIV in the UK.

Our FGDs were smaller than those typically seen in social research (Finch et al., 2014). However, we found that the small number of participants had a positive impact on the group dynamics and discussions. The smaller group discussions felt more personal and intimate with conversations often more organically led by participants rather than directed by facilitators, which would be expected in larger FGDs (Finch et al., 2014). Interviews with service providers also offered additional perspectives to how services are organised and delivered for people with HIV and how these have adapted over time. Although we did not record the demographic characteristics of key informants, we were able to speak to a diverse range of people according to their occupation. Due to the study design and approach, our findings may not be generalisable to other contexts but could be transferable in nature (Lewis et al., 2014). The London-based FGDs recruited predominantly people with HIV who had previously participated in research and therefore may not represent the most marginalised, socially disadvantaged or underserved communities living with HIV.

#### 4.3. Implications of study

The formative research provides insights which will inform the design and delivery of a health and well-being intervention based on health coaching and social prescribing to be tested through a randomised control trial (as part of the NICHE programme of research).



Insights from the FGDs and interviews have emphasised the importance of maintaining an individual component rather than 'one-size-fits-all' approach to the intervention which underpins the person-centred design of NICHE. A persistent theme across focus group discussions related to stigma. Although some social networks and support groups can have a positive impact on sense of belonging, sense of self and feeling part of a community, we also heard examples of stigmatising experiences and discriminatory practices which continue to be experienced by all demographics. Therefore, intersectionality and considering the needs of the 'whole person' and the multiple forms of inequality and disadvantage they may be contending with, is fundamental. For example, intersecting structural inequalities related to immigration, housing, finances and employment may be raised by people with HIV and a person-centred model of care could begin to identify what support and resource are required to begin to address this. Social prescribing is one approach to person-centred care. Although social prescribing may not be able to address upstream factors (Moscrop, 2023) or reduce inequalities (Gibson et al., 2021), research suggests that non-medical referral pathways may lead to more equitable access to support by those most in need (e.g. people from deprived areas) (Bu et al., 2024). It is also important to consider how experiences and perceptions intersect with the hopes, desires and ambitions of people living with HIV.

## 5. Conclusion

People living with HIV continue to experience discrimination and stigma which impacts on perceived sense of self, self-worth and broader mental health and well-being. Despite advancements in the treatment of HIV and life expectancy for people with HIV, 'living well' also largely centers around life beyond HIV status, to include good social support, supportive intimate relationships, and other psychosocial factors. These continue to be heavily influenced by HIV-related stigma. Focusing on person-centred care provides an opportunity for HIV care in the UK to remain world-leading and ensure people with HIV age well and live long, fulfilled and happy lives.

## CRediT authorship contribution statement

**Vasiliki Papageorgiou:** Writing – review & editing, Writing – original draft. **Lucy Cullen:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis. **T Charles Witzel:** Writing – review & editing, Investigation, Formal analysis. **Alex Sparrowhawk:** Writing – review & editing, Methodology, Funding acquisition, Formal analysis, Conceptualization. **Flavien Coukan:** Writing – review & editing, Investigation. **Janey Sewell:** Writing – review & editing, Project administration, Investigation, Funding acquisition. **Alison Rodger:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Conceptualization. **Carl May:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Formal analysis, Conceptualization. **Fiona Burns:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Formal analysis, Conceptualization.

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## Declaration of competing interest

None to declare.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.socscimed.2025.118109>.

## Abbreviations

FGD	Focus group discussion
GP	General Practitioner
LGBTQ+	Lesbian, gay, bisexual, transgender, queer, questioning and more
MSM	Men who have sex with men
NICHE	The Needs Informed model of Care for people living with HIV (NICHE) programme
PrEP	Pre-exposure prophylaxis
TasP	Treatment as prevention
U=U	Undetectable = Untransmittable

## Data availability

The data that has been used is confidential.

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