Positive Voices

the national survey of people living with HIV

BEYOND POSITIVE VOICES

Qualitative Research on High Levels of Unmet Needs for Key Populations Living with HIV

Acknowledgments
A special thanks to all the people living with HIV who took part in Beyond Positive Voices project, the facilitators who drafted the foreword and all who volunteered their time and expertise. We are grateful to all participants who volunteered to be photographed for this report in order to give a face to HIV and help break down the stigma surrounding HIV. A special thanks to UKHSA for their help to reach out to the survey participants.

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Thanks to ViiV and Gilead for their support.

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Foreword

Our understanding of how HIV affects us as individuals, both physically and socially, isn't without recognition to the lived experiences of those who are living with and affected by HIV throughout the last five decades; the wealth of knowledge, wisdom, and truth in which we share is done with care and a willingness to seek change not only for ourselves, for those living with HIV, but also for those who are unable to speak up, for now. There can never be anything about us without us.

It is with the ethos "nothing about us without us" which is at the core of Beyond Positive Voices, as someone living with HIV who has provided time and lived experience to many a report and study; being able to, as a community, see the data, understand it and disseminate it between ourselves supplies us a refreshing sense of autonomy over our "statistical" lives; reminding those that read the following, we are people and we are here, living life.

However, there is an uncomfortable truth to be faced when listening to our lived experiences; you may not always like what you hear, and that's okay – for change to take place we must first sit with our discomfort and acknowledge what meaningful change would feel like. For many of us living with HIV we have seen the leaps and bounds we have made in the medicalisation of HIV; from the early years of multi-pill cocktails, all the way to modern-day treatments such as injectable ARV's and once weekly pills. We know that HIV doesn't have to define us, and yet for many it still does, as a manageable chronic condition, HIV still carries so much weight and history behind it; where the burden of such diagnosis sits on the shoulders of us living with HIV. We shouldn't have to just survive with HIV, we should be encouraged to thrive in spite of our HIV.

Let this report bring the beginning of a new era of change for supporting people living with HIV, we must ensure that all people living with HIV have access to the support they need in order to do more than just survive.

So, what can we do? There are many actions to be taken from Beyond Positive Voices, but to summarise; we all have a role to play in ensuring that HIV doesn't hold any of us back, we must take urgent action to break down the barriers affecting key populations as highlighted throughout Beyond Positive Voices, we have to explore how U=U can be more widely implemented in an understandable and meaningful way for everyone to reap the benefits of such life changing health messaging, HIV peer support must be accessible with equitable access nationally for all living with HIV.

As you read this report, allow space for it to teach you something new; sit with what it has taught you and let it shape how you play a part in a modern era of HIV and how we can all work towards meaningful change for all living with and affected by HIV.

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Introduction

Understanding better the daily lived experience of people living with HIV is critical to both informing the right interventions that can support a high quality of life, and in making progress towards ending the onward transmission of HIV. This project brings together the voices and experiences of people living with HIV who tend to report higher levels of unmet need. They are often the most marginalised and have intersecting inequalities which need to be properly understood and responded to.

Through focus groups with women, migrants, people aged over 50 and trans*[1] and gender diverse people, National AIDS Trust (NAT) and Positively UK heard the unique challenges they face in managing their HIV status alongside other aspects of their lives. We provide a set of reflections and recommendations that outline how structures and systems can improve their wellbeing and quality of life, based on experiences and thoughts revealed during these discussions. We also suggest some ideas for how the Positive Voices survey could be adapted to gather more meaningful evidence for these individuals living with HIV in the future.

[1] The term trans* is used to emphasise the breadth of identities encapsulated in the term. Where used in this report, the term trans* is intended to mean those identifying as transgender, non-binary or gender diverse.

What is the Positive Voices survey?

Positive Voices is a nationally representative survey of people attending HIV specialist care in England, Wales and Scotland, and its results make up the most comprehensive quantitative research available in the UK on daily experiences and quality of life of people living with HIV. It is conducted by the UK Health Security Agency (UKHSA) and includes participant-reported data on a range of topics, including HIV knowledge, diagnoses and treatment, satisfaction with healthcare, stigma and discrimination, met and unmet health and social care needs and health-related quality of life. The first round of the survey was conducted in 2017, and the second in 2022. For the second round, the survey included views and experiences of 4,540 people living with HIV, representing approximately 1 in 20 people living with diagnosed HIV in England, Wales and Scotland.

Why have we done this work?

Positive Voices provides us with a valuable snapshot of the daily lives and experiences for people living with HIV, and highlights where interventions are needed to continue working towards the UK government's goal of ending new HIV transmissions by 2030, improving quality of life and achieving zero stigma. However, to truly understand where progress is being made, and what the barriers are to further progression, there is a need to add to Positive Voices' quantitative data with qualitative, inclusive and holistic evidence. By speaking directly with people living with HIV, building on the knowledge provided by the survey, we are able to add the nuance and detail needed to supplement the Positive Voices framework and identify the most effective policy response. Moreover, this work provides a platform for people living with HIV to take ownership of the research—interpreting the data and offering guidance on the way forward. Co-producing this work with people with HIV is instrumental in building community capacity and addressing stigma at its root.

This project is a continuation of the Changing Perceptions project, which was conducted by NAT and Positively UK in 2018. Changing Perceptions was a community-led analysis of the 2017 Positive Voices data, which culminated in the development of three reports on unmet needs, relationships and social acceptance and stigma. Digital stories were also made available on the Changing Perceptions website.

Who did we speak to?

Throughout the evidence-collecting phase of this project, we held discussion groups with women, people aged over 50, migrants and trans* people living with HIV. These groups were selected as their responses to the Positive Voices survey revealed that they reported poorer health and wellbeing outcomes than others. Some examples include trans* people reporting higher levels of depression and mental ill health than others, self-stigma being higher among women than other groups, and older people and women reporting the lowest trust in the U=U concept. Migrants were chosen as Positive Voices does not collect data on this group specifically, but we know that migrants living with HIV in the UK experience intersecting health inequalities and social barriers that can make managing their status and daily life more difficult. Trans* people were also selected as only 67 people living with HIV who identify as trans*, non-binary or gender diverse were included in the Positive Voices survey report, so additional perspectives and representation from this group were deemed invaluable to understanding their experiences.

Key themes and recommendations from the research

The reflections from each of the groups on what people want to see change to respond to their needs and improve their quality of life are set out at the end of each section.

However, across the groups some key themes emerged which lead to overall recommendations for policy makers, health care professionals, and others:

The lack of knowledge and awareness of U=U causes ongoing difficulties and the continued misunderstanding of HIV transmission leads to ongoing stigma and discrimination in both healthcare settings and in all areas of life.

Action: DHSC must prioritise and support the raising of awareness of U=U as part of the HIV Action Plan in all sectors and to tackle stigma.

Action: Healthcare and social care settings - particularly those working with key populations and communities such as midwifes/obstetrics and those supporting older people - must have training and policies in place to understand how to respond appropriately to the needs of people living with HIV, reduce stigma, and ensure fair treatment in accessing services.

Systems and data need to be better joined up and evolve to give people the best care and experience – whether between HIV clinics and other parts of the health system, in the management of co-morbidities, and in social care, people’s experiences are disjointed and leads to fragmented care, delays, and emotional exhaustion having to repeatedly explain or self-advocate.

Action: NHS systems, platforms, and databases must be reviewed to ensure best streamlining and availability of the right data so that people can receive the best continuum of care.

Action: In HIV clinics and across the NHS databases and systems need to be reviewed and updated to ensure that they can record the correct pronouns for people, and appropriately separate sex and gender.

Peer support is crucial, but is not equally accessible and available – geographic inequalities reduce the ability of people to receive peer support and leaves people isolated and less able to navigate health system and respond to needs and challenges in their lives.

Action: DHSC, in partnership with ICBs and local authorities, should ensure the availability and accessibility of peer support for people living with HIV, incorporating in-community, in-clinic and online methods.

Methods

Initial discussions were held between NAT, Positively UK and UKHSA to determine which groups to focus on and how participants for these would be recruited. Once these groups were identified, UKHSA contacted, via email, the relevant people who had responded to the Positive Voices survey in 2022 and highlighted that they would be willing to participate in future research. If interested, these individuals filled out a registration form capturing demographic information including gender, race, age, immigration status and length of time living with HIV. We used this information to select participants for each focus group, ensuring that, to the best of our ability, the group was diverse and represented varied experiences within the predetermined four group categories. It was decided that four in-person focus groups would be held, one with each of the agreed upon demographic groups.

Focus groups were co-facilitated by a member of NAT staff and a member of Positively UK staff, the latter of whom was living with HIV and members of the specified cohort, i.e. we ensured that a trans* co-facilitator was present for the trans* discussion group, and so forth. Questions and topics covered in each focus group were based on data for the relevant individuals from the 2022 Positive Voices survey. These were utilised as a starting point, but groups were not formally structured and followed any and all topics that participants deemed relevant to their experiences living with HIV.

Limitations to the study

Some miscommunications during recruitment led to some individuals attending the in-person session who did not identify as trans*, meaning that parts of the discussion were perhaps more restrained, and experiences could not be shared completely and with full understanding. To gather a more representative group and understand their perspectives, it was decided that a fifth, virtual focus group with trans* people living with HIV would take place.

The intention of the project was to keep participants to those who had completed the Positive Voices survey in 2022. Because of limited interest, for the second trans* focus group, we invited any trans* people living with HIV to take part, regardless of their involvement in Positive Voices or not. We felt that the depth of their experiences would enhance the research, and would provide useful feedback for Positive Voices, even if they had not directly taken part. This decision also marked an important step in community building and co-production with a group that is often marginalised and unheard.

It is important to note that this research does not represent the views and experiences of every person living with HIV from each of these demographic groups.

Trans*, non-binary and gender diverse people

Summary: views from trans* people

- The intersection of being trans* and living with HIV is extremely challenging due to combined stigmas and forms of discrimination, which are exacerbated by other forms of marginalisation such as those associated with race, immigration status, mental health and housing status. This intersection underpins most of the challenges that trans* people living with HIV face
- Life satisfaction among trans* people living with HIV is low due to these intersectional challenges, and the fact that accessing healthcare for HIV and gender-affirming care, while coming to terms with gender identity, presents many challenges
- Participants felt that the U=U campaign is too complex for the general public to understand and increases stress when having to explain it to people
- Sharing HIV status is a scary and stressful experience, particularly when coming out as trans* to loved ones is also a concern
- Transphobia is rife within the healthcare setting, including in HIV clinics
- Early intervention in the form of mental health support is crucial for trans* people living with HIV
- Many trans* people feel that they do not 'fit in' to HIV peer support groups
- High levels of unmet financial need among this group are largely due to the work exclusion that many trans* people face

> ***"I have always thought of having HIV and being trans* as a double-edged sword – you can't hold one, and they both exacerbate each other"***

Intersecting identities: being trans* and living with HIV

The primary theme of the discussions with trans* people was the challenges that are presented by the intersectionality of existing as a trans* person who is living with HIV. Participants shared that trans* exclusion exists everywhere and simply just existing as a trans* person living with HIV is scary. If someone experiences further intersections of marginalisation – being a migrant, person of colour, neurodivergent or homeless, for example – fear and stigma are exacerbated even further. It was discussed that interventions don't exist for intersectional and marginalised groups, which is why they intervene themselves in the form of community building. Participants felt that it was these communities that drive any sense of belonging for them and provide them with the information and resources they need to try and live well, as society's structures and systems are not equipped to do this.

Life satisfaction

The 2022 Positive Voices survey results illustrate that among all people living with HIV, trans* people are, overall, struggling the most to live well. Life satisfaction scores were lower in this group than any other. When asked why they think this may be, participants spoke to the aforementioned intersectionality of being trans* and living with HIV, among others, and the layering of challenges that each of these brings. One individual shared that *"it's almost impossible to live life without harassment as a trans* person living with HIV … things that happen outside affect how you feel inside"*.

Participants shared that accessing medical care as a trans* person – whether for gender-affirming care or HIV care – is extremely challenging due to long waiting lists, feelings of shame and experiences of stigma, leading to distrust in, and discomfort with, the healthcare system. These barriers are extremely difficult when trying to process your identity, both as it relates to your gender and HIV status. Participants shared that they have had no support around this from the healthcare system, and that this comes from elsewhere – within their own communities and from organisations supporting them with other aspects of their lives.

The support one individual received from a homelessness charity has been far more holistic than focusing solely on housing, and they attribute their support worker from this organisation for saving their life.

Within the discussions, participants suggested that the way Positive Voices asks about life satisfaction feels like a tick box exercise, that shows no understanding of the complexities of being a trans* person living with HIV. While it was acknowledged that there must be some level of this to gain quantitative data, individuals felt that if this question could somehow be broken down to consider intersections of marginalisation, this would both gather more meaningful data and cause respondents to feel more understood.

Attitudes towards U=U

Across the groups, there were mixed feelings from participants about U=U as a campaign. It was largely agreed that the concept of U=U feels like a relief and allows individuals to have freedom in their sexual lives and relationships; however, there was also a consensus that if the general population does not understand the campaign of U=U, then it seems pointless. Some felt that the words 'undetectable' and 'untransmissible' are too difficult to understand, as other groups have mentioned. One participant also shared that the phrase is, due to advances in science, now technically incorrect – some machines can still detect untransmissible levels of virus in the blood. This participant shared that they have had people accuse them of lying because of this, when they have tried to explain the concept of U=U to people around them. Overall, the groups felt that the concept of U=U is welcomed and helps people to live more freely, but the campaign associated with it is overcomplicated and adds more stress to them when they have to try and explain what it means repeatedly in social situations.

Sharing HIV status

Overall, it was agreed among the groups that even when sharing your HIV status goes as well as it can, it is still a scary and stressful experience to tell someone in your life this information out of the blue. For many participants, coming out as trans* to their loved ones is another difficult challenge, meaning that some have held back from sharing their HIV status as people around them are still processing their gender identity. One participant shared that it's very painful to not be able to be open and honest with their family because of this. Another person has had extremely negative responses to sharing their HIV status, which has led them to abstain from engaging in relationships entirely.

During the discussion about status sharing, the question from Positive Voices that asks, "are you ashamed of your HIV status?" was raised. Survey data show that results from this question show that almost all demographics are more ashamed of their status than cisgender, white, gay men are. Some participants shared that it feels like this group almost has a 'monopoly' on HIV and HIV healthcare, and that as trans* people, they feel overshadowed and left out of the wider conversation around HIV. The use of the umbrella term LGBTQ+, which groups trans* people together with gay men and other identities, can sometimes obscure the specific experiences and needs of trans* communities. This generalisation risks erasing important differences and may hinder the development and tailored responses that truly reflect trans* people's lived realities.

Experiences within healthcare

HIV clinics

Despite the rating of HIV clinics in the 2022 Positive Voices survey among trans* people being 8.8 out of a maximum 10, this was the lowest rating among all genders and demographic groups. Perspectives on this among our trans* participants were mixed. Some participants in our discussions shared experiences of transphobia, misgendering, misunderstanding and stigma in their HIV clinics. These experiences included the use of incorrect pronouns, the use of dead names, and clinicians constantly changing so a need to keep re-introducing and re-explaining upon each visit. Participants shared that it feels scary to identify yourself, and it is disheartening when this is constantly not taken seriously by health professionals. One non-binary participant shared that they are always treated like a gay man in these settings; for example, being offered certain tests that are not relevant for them and do not reflect their experience as a non-binary person. They explained that this happens every visit, as they never see the same nurse or doctor twice. The group felt that doctors are still being educated about gender by their own patients, which is neither appropriate nor acceptable in a care setting. The groups discussed how forms at clinic still ask about sex and gender as though they are the same thing, expressing that they "don't want to be 'other'" every time they fill out a form about themselves.

While 91% of trans* respondents said they felt listened to by staff at HIV clinics, this was the lowest of all groups, and it is important to note that the trans* cohort in the survey was small at 67 respondents so not entirely representative of the whole trans* community. Participants in our discussion asked what exactly it means to be 'listened to' – in their experiences, they do not feel listened to, as this would encompass being gendered correctly after explaining the first time, sitting with a clinician with enough time to discuss their life and building a rapport with staff. These are aspects of care that they are not receiving. This is even worse in non-urban areas, with one participant who lives outside of London sharing that *"I have never attended a clinic outside of London – it's not worth it"*.

Positive experiences in HIV clinics were also shared. Some participants felt clinics are potentially less prejudicial than settings like GPs, for example, as they are seeing higher proportions of queer people. This translates into the care offered, as one participant shared they receive more thorough STI checks at their HIV clinic, and that their clinic has previously picked up on things that their GPs have not. One individual explained that this is especially relevant for trans* people living with HIV as many trans* people experience work exclusion in mainstream fields and may be engaged in sex work as a more welcoming trans* space.

Another important consideration for trans* people living with HIV is that there are some trans* people who choose to self-medicate when it comes to taking hormones, due to long NHS waiting times and limited access to gender-affirming care. One of our participants shared that their HIV clinic supports them to ensure that they self-medicate safely, sending them results of blood tests so they can check their hormone levels and take the correct dose. They spoke very highly of their clinic in doing this, helping them to affirm their gender independently in the face of systemic barriers that prevent or delay many trans* people from doing so.

GP practices

Among trans* people responding to the 2022 Positive Voices survey, GPs were rated at a 5.4 out of a possible 10, coming in lower than the average for all people living with HIV at 6.5. Participants in our focus groups agreed with this, sharing that they had had their status shared in front of others in waiting rooms and experiences of misgendering and transphobia in these settings. Individuals felt that GPs they had encountered are not good at signposting to support services, which is why many marginalised and queer people rely on their self-built communities. It was noted, however, that most of these communities are functional in cities, and a much harder to find in rural areas. Groups felt that trans* people should be able to live wherever they want, as anyone should. Relying on communities to provide each other with important information about care and support should not be the top priority, and this should be happening within primary care settings.

Mental health care

It was stressed among all participants that for trans* people living with HIV, intervention for mental health support needs to come in early, for individuals who are questioning their gender identity and/or newly diagnosed with HIV. The intersection of these two challenges, as previously discussed, requires support to navigate, which is not routinely offered. Individuals felt that this should be coming from the NHS and local authorities but is instead coming solely from the third sector. The consensus was that charities are fantastic, as they understand the communities they serve as well as the LGBTQ+ experience; however, they are increasingly overwhelmed and at capacity.

Participants agreed that speaking to a GP for the first time about being trans* is a humiliating experience. There should be a point of contact from this first discussion to support individuals through this process. As previously mentioned, one participant shared that their primary support has come from a homelessness charity, which they became engaged with when they had nowhere to live and nowhere else to turn. While this person is now living well and has continued support from their contact at this charity, they urged that trans* people living with HIV should be able to access this kind of support *"before their life falls apart, as mine did"*. Navigating constant transphobia and HIV stigma in conjunction with life's other challenges can have drastic mental health impacts on an individual, and participants shared that many members of this community have struggled with substance abuse, suicidal ideation, homelessness and more, because of not receiving the appropriate support when it was initially required.

Additionally, some participants shared their experiences of trying to access diagnoses for neurodivergence and other mental health conditions. Through their trans* communities, they had heard stories of infantilisation and removal of access to gender- and life-affirming care because of sharing these aspects of their mental health. These stories are shared within communities so that people know where they can and can't go to keep safe as trans* people. This reiterates how heavily trans* and queer people lean on their communities but also highlights how trans* people are not taken seriously when it comes to healthcare, both physical and mental.

Peer support

Our trans* participants felt that while the concept of peer support is excellent, it does not feel aimed at their community. Experiences were shared of feeling out of place in peer support groups that all feel aimed at cisgender gay men. One of our non-binary participants shared that they don't fit the 'non-binary aesthetic' but also feel they don't fit with trans* people, and that they feel there is no peer support available where they would feel they fit in. They explained having to teach their therapist what it means to be non-binary and feel frustrated that they are paying to have to teach someone who is meant to be supporting them about their gender identity. Another participant, a trans* woman from Colombia, felt similar, and has struggled to find peer support groups as a Latinx trans* woman.

Unmet financial needs

Positive Voices data show that trans* people living with HIV have huge levels of unmet need, particularly around money. 72% of respondents in this group reported that they did not always have money to meet basic needs, and a third of trans* respondents were in receipt of a means-tested benefit (compared to a fifth in the general respondent group). We discussed this in the focus groups, and participants largely agreed that the work exclusion trans* people face is a large contributor to these barriers. Individuals shared that they often leave their pictures off CVs so they are not judged from the outset and have had experiences of this judgement of their appearance when they arrive at a job, as they do not present in the way a potential employer would expect.

One participant shared their experience of working in nightlife, and feeling 'stuck' there, because it's one of the only places they feel accepted to work as a trans* person.

Reflections on how to improve quality of life for trans* people

- HIV clinics must be aware of their trans* patients and work to update their knowledge and records to use correct pronouns, list sex and gender separately and provide consistent, inclusive care regardless of which healthcare professional is providing care
- Trans* individuals living with HIV must have access to increased levels of mental health support, to help them navigate the intersection of coming to terms with both their gender identity and HIV status, if needed
- An inclusive peer support offer must exist for people living with HIV across the entire gender spectrum – trans* men, trans* women, non-binary and other gender diverse people
- Positive Voices should ask about life satisfaction in a way that considers complexities of existing within multiple marginalisations of society – not just a 'one size fits all' question

Migrants

Summary: views from migrants

- Participants felt the stigma they experience was more related to their status as a migrant than the fact they are living with HIV
- Differences between HIV care in the UK and participants' home countries varied – some had more holistic care back home, while others feel their standard of care in the UK is much better
- Feelings around the U=U campaign were mixed, and none had been aware of it before coming to the UK
- Not all participants knew what peer support was during the focus group, but all felt that this would be beneficial in reducing shame and self-stigma upon first being diagnosed

> *"I realised my life is split into before HIV and after HIV – after HIV is the best life I've ever had. I have happiness, I'm going to live my life like it's my last day. I decide to live"*

Positive Voices does not collect data directly for migrants as a demographic group, as it does for the other three groups that were selected for this project. Migrants were a group chosen for this project as we are seeing rising numbers of new HIV cases in the UK being attributed to those continuing their care here after being diagnosed elsewhere. In 2023, 53% of new diagnoses were reported to UKHSA as being in people continuing their care in the UK. It is therefore crucial to understand experiences of this group managing their HIV status in the UK. In the discussion, topics covered included differences in HIV care across countries, discussing HIV status within migrant communities in the UK, attitudes towards U=U, the importance of peer support and barriers migrants face to living well with HIV in the UK.

It is important to note that migrants involved in this research were largely from Central and South America, and their experiences and views may not reflect those of individuals from other countries living with HIV in the UK.

Differences in HIV care between home countries and the UK

There were varied experiences among participants when comparing their HIV care in their home country and the care they have received upon coming to the UK. A participant from Colombia shared that their experiences at home were more holistic and did not just focus on their HIV status specifically; they felt that GPs in the UK have limited knowledge in comparison. Conversely, another participant from Mexico has had a better experience in the UK than at home, sharing that they are treated with far more respect and have been given more opportunities, such as participating in a new drug trial. This person attributes the progress they have made in feeling proud of their HIV status to this high standard of care they are receiving in the UK, and shared that it has inspired them to make the most of their life.

Throughout the discussion, it became clear that the UK experience differs hugely based on a person's geographical location, with those in urban areas – especially London – being offered more opportunities like this than rurally and elsewhere. This is an experience shared by all demographic groups in this project and is not specific to the migrant community, so must be considered with urgency.

Experiences of stigma

Participants shared that they did not feel that they are treated differently to their non-migrant counterparts when it comes to their HIV care. However, some individuals did share experiences of racism, which has posed barriers to accessing information about HIV care and peer support.

Some were not aware that everyone in the UK should be able to access treatment, regardless of immigration status. One participant shared that people in their neighbourhood spoke to them very slowly in a patronising way, despite their English being of conversational level. It was suggested among the group that experiences like this are worse in rural areas compared to cities. Participants also shared some experiences of stigma within dentist settings and at tattoo parlours, which is consistent with the experiences of other groups.

Knowledge of U=U

Every person in our focus group shared that they had no knowledge of U=U before arriving in the UK, and that this campaign is not a message that is spread in their home countries. Participants largely felt positive about it upon learning it and have trust in the concept. Some felt that the words undetectable and untransmissible are hard to understand and may be too complex for some, which undermines the idea of it being an easy message to spread.

Peer support

When asked about peer support, not everyone in the room during the focus group knew what this meant. Not all participants had received an offer of peer support from their HIV clinic in the UK. Just one person, from Mexico, had been offered peer support in their home country. When the concept of peer support was explained, all participants felt that this would be beneficial for them, with everyone agreeing that it would have helped their feelings of shame and self-stigma had they been offered this upon their diagnosis.

Reflections on how to improve quality of life for migrants

- Ensure that all people coming to the UK living with HIV are aware of how to access care and medication, as their experiences of this in their home countries could be very varied and different to the UK
- Highlight the opportunity to receive peer support to all migrants entering the UK and living with HIV
- Ensure that the message of U=U is also explained in plain language

Women

Summary: views from women

- U=U needs to be better understood by the general public
- When it comes to sharing status, women feel a constant tension between being honest with those around them and protecting themselves in potentially unsafe situations
- HIV-related stigma is rife in relation to pregnancy, childbirth and breastfeeding, which is a particular concern for women living with HIV
- Symptoms that can relate to both potential side-effects of HIV medication and the menopause often mean that one or the other is overlooked by doctors
- Differing systems between geographical regions and health trusts are confusing, and both remote and in-person support are needed to support the varied needs and lifestyles of women

> ***"One size fits all does not work. We are all different shapes and sizes, different to men, tests and studies are often done on men"***

Attitudes towards U=U

In the 2022 Positive Voices survey:

- 88.2% of women said they were aware of U=U, but only 50.8% strongly believed it to be true
- Over ¼ of women responding either didn't know what U=U means, are not sure or do not believe in it

When asked about this in the discussion group, there was a sense among the women that while the concept of U=U is understood, belief in it would be more grounded if more people knew and spoke about it, and that challenges associated with HIV status, including stigma and still needing to 'come out' about one's status are not alleviated just because of U=U. The group agreed that there should not be a need to 'come out' and the onus of educating the general public about HIV and about U=U should not be on the community of people living with HIV.

Participants felt that those with more access to peer support or information, as well as those who may be famous, well known among communities or in the public eye – and therefore have higher levels of privilege – will find it easier to trust in U=U and share their status with others than those who cannot access these resources. In addition, those who knew people living with HIV in their life also shared that they can trust more in U=U and come to terms with their status as they can 'see it's okay'.

Sharing HIV status and navigating relationships

There were mixed feelings among the group about navigating relationships and sharing HIV status with people in their lives. Many women shared that they have a fear of dating and poor self-esteem as a result of having to repeatedly have the same conversation and worry about how the other person will react. Some women in the group shared that they have not sought out new relationships for many years as the fear around sharing is too much to deal with, which contributes hugely to feelings of isolation. Others, who have entered into relationships, felt that living with HIV has meant they have settled for things that haven't been okay, and that their HIV status has had a detrimental impact on their self-esteem and confidence. In some instances this has led to dangerous situations where ex-partners have used participants' HIV status against them or as a bargaining tool, or have become violent or angry, putting women in unsafe situations for sharing their status. Participants also noted that some women may be financially dependent on a partner, or living in poverty, which may influence how they approach sharing their status, as it may not be financially safe for them to leave a relationship if this information is not received well. This aligns with data from Positive Voices, where almost a third of women respondents reported being in receipt of a means-tested benefit – almost double that of the same proportion in men who responded.

Women in the group agreed that there is a constant tension between not wanting to keep a secret and protecting yourself.

There is a heavy weight felt to consider the feelings of others – which, the group noted, is a universal experience for women anyway, and is something that living with HIV only adds to. Ultimately, though, the group held the attitude that being able to allow certain people to know their HIV status, or not, was how many people feel in control of their HIV. One participant shared that living with HIV means that they have an increased level of self-awareness about their body and health, provides perspective and forces them to be discerning about who they keep in their life.

Experiences within healthcare, social care and self-care settings

HIV-related stigma within the healthcare system is unfortunately still happening at unacceptably high levels, with more women than men reporting in Positive Voices 2022 that they felt they were refused healthcare because of their HIV status. There are experiences within healthcare settings that are unique to women, including pregnancy and childbirth, and the women in our discussion group shared that they felt judged for needing a caesarean section, seen as 'too posh to push' and the embarrassment that came with having to explain why this is medically necessary. The women expressed that there is a prejudice around not breastfeeding your child, and a constant worry for them around having to continually explain why they may not be able to. One of our participants shared that she was advised to never have children because of her HIV status, and not doing so has been her biggest regret in life. It is worth noting here that most participants in the focus group for women have been living with HIV for some time, so their experiences around having children, childbirth and breastfeeding reflect concerns among people diagnosed some time ago. Scientific and medical advances over the last 20-30 years mean that some of these experiences will no longer take place in the UK for women who hope to have children while living with HIV.

Participants also shared experiences of HIV-related stigma outside of pregnancy and childbirth settings. One woman is undergoing cancer treatment and continually needs to explain to her consultant that this is a separate issue to her HIV status – this has reached the stage that she carries around a piece of paper with her saying 'don't talk about my HIV' so that her status is not shared in communal waiting rooms or around others. The group all shared stories of feeling judged by pharmacists, with looks or questions, when picking up medication from a clinic or pharmacy, and there were multiple stories shared of being asked how HIV had been acquired mid-appointment or mid-procedure. One participant shared that her audiologist left the room to put on gloves when they learned about her HIV status during a routine hearing test. These experiences have also extended to social care, with one participant explaining that when her children were removed from her care due to mental health concerns, her HIV status was referenced a lot, was shared with her child's school without her consent, and she was asked to prove that she wasn't using needles. Her child was stabbed with a pencil at school and staff refused to treat them due to their mother's HIV status.

Every woman in the group said that because of these negative experiences, and the fear of them continuing to happen, they do not share their status when asked on forms at many health or beauty clinics, and would only do so where relevant, like at the dentist. It is clear from these extensive negative experiences that staff across health, social and self-care sectors have not been provided with up-to-date education or training about HIV, its transmission and the impacts of medication and stigma. Public awareness and training of staff in these areas must be prioritised if we are to end stigma and discrimination in these environments and provide women living with HIV with the optimal level of care.

Side effects, HIV medication and the menopause

In 2022, the Positive Voices survey found that 8.8% of women completing the survey had experienced side-effects from their anti-retroviral therapy in the 4 weeks prior to completing the survey. The women in our discussion group all felt that this was an underrepresentation of the side-effects that they experience, and wondered whether side-effects like fatigue and high cholesterol have become so 'normal' for women living with HIV that they are forgotten about, or not considered 'bad enough' when answering this survey question. This will particularly be the case for women who have been living with HIV for a long time, and may have initially been on older forms of medication that have long-lasting side-effects into the present day. The women in our group suggested that asking about hidden side-effects may help gather a more accurate response to this question.

Women also shared that there is very little information available about the life cycle and ageing for women in general, let alone women living with HIV, and how medication can impact these different stages like menopause and perimenopause. Participants shared that changing hormone levels sometimes means that side-effects of HIV medication are felt more intensely, mentioning memory loss, headaches, changing bone density, sex drive and weight gain. Women in our discussion felt that healthcare professionals did not consider the interplay between HIV status, medication side-effects and menopause when being told about these symptoms and blamed them on one or the other. Some shared they did not feel listened to, were 'just expected to get on with it' or to simply 'eat less and move more'. One participant pointed out that this is very difficult to do when one of the overwhelming symptoms is fatigue. Women shared a concern across the group about how side-effects like these will be managed as they age, and may need to be looked after within the social care system, where HIV-related stigma is often seen at high levels.

Remote vs in-person services

Over a quarter of women responding to the 2022 Positive Voices survey said they never have access to the internet to access health records confidentiality, yet satisfaction with remote services was higher among women than other genders. This mixed picture correlated to the discussions with women in the focus group, and frustrations were aired around how different regions and hospital trusts have different systems, making accessing information and medication confusing. Some women felt that accessing health records online is too complicated and the fatigue that comes with trying to overcome this means that forms will go uncompleted. Women of Black African ethnicity in the group shared that women in their communities have lower digital literacy and it would not be uncommon for them to have no access to devices or technology, meaning that if they live in an area where health records and medication are accessed online, there would be huge barriers to accessing their HIV care.

In contrast, one woman shared that during the COVID-19 pandemic, funding was removed in her area for local clinic and remote services and has not been re-instated, meaning she is expected to travel 25 miles each way to her clinic, twice a year. Barriers to affordability, transport, mobility and time can all make this extremely difficult or even impossible for some. One participant has her medication delivered to home, which is a system she is happy with, while another shared that she has to go to a pharmacy to collect it, which is an experience that can 'out' her status to others when she is counting out medication at the counter and bringing a large bag in order to carry her 6 months' supply home. Women also shared that they are often chasing their local pharmacies for where and when their medication will be delivered, and that this is not a smooth process.

While the value of in-person services was recognised in the group, one woman shared that she feels uncomfortable attending sexual health clinics as an older person, who is 'not having sex', being surrounded by younger people who are 'judging why I am there'. The group discussed that a form of neutral outpatient clinic might suit older women better, where you could be attending for any number of reasons rather than solely for sexual health.

Reflections on how to improve quality of life for women

- Education and awareness about HIV and U=U must be more widespread, with the onus to inform others not sitting solely with people living with HIV – will help increase trust in U=U and safety for women in navigating dating and relationships
- Training in health and social care staff, as well as in the beauty industry, must be prioritised in order to reduce stigma and discrimination in these environments – particularly in areas like midwifery and obstetrics where women living with HIV are being treated differently
- Side-effects of long-term medication and how these interact with life stages like menopause and perimenopause for women must be considered and addressed with support by health professionals
- Ways of accessing health records and medication must be streamlined to reduce confusion with different platforms and systems, and flexible access to remote and in-person services as appropriate must be made available nationwide
- Women living with HIV must continue to be meaningfully involved in conversations about their experiences and care, and opportunities must be proactively created for their expertise to be recognised, valued and acted upon

People aged 50+

Summary: views from people aged 50+

- U=U as a campaign is of less relevance to older people living with HIV as there is a feeling that the older generation within the general public may not ever change their stigmatising views
- Concerns around ageing with HIV include:
- Managing co-morbidities and ensuring drugs prescribed for these do not interact with HIV medication
- Entering the care system where many staff are not educated around HIV and where HIV-related stigma is prevalent
- Determining where to live so that it can be ensured that HIV care received is of a high standard
- In general, feelings of self-stigma are lower in older people living with HIV, as they have 'moved past' feelings of shame – our participants have been living with HIV for quite some time
- Older people living with HIV are less concerned about networking with other people living with HIV, and would prefer socialising to be focused around activities

> *"I am choosing where to move based on the care I might receive there"*

Attitudes towards U=U

Results from the 2022 Positive Voices survey show that trust and belief in U=U decreases with age. Participants in the 50+ focus group felt this to be accurate. While acknowledging that not being able to pass HIV on is obviously a positive thing, the group's general attitude was that older people living with HIV care less about public knowledge, and that U=U as a campaign is not overly helpful to them. Participants felt that it's only helpful for those close to people living with HIV, and that the general public doesn't care. There was a level of pessimism among the group about this attitude ever changing among the older demographic.

Participants in this group felt that in order for the U=U message to gain traction and spread among the general public, more people of influence need to speak up. The group spoke highly of Princess Diana and the huge influence she had on the public perception of HIV – participants felt that there had not been a figure as impactful since, and that this would help people understand U=U, particularly among older generations.

Ageing with HIV

Much of the discussion in this group focused on particular concerns for participants around getting older, and managing their HIV alongside challenges that any ageing person might face. Participants expressed concern around how side-effects of their medication might manifest as they get older, and highlighted the uncertainties that exist for them in this arena, considering they are one of the first generations of people to age with HIV.

Many individuals shared that they are considering where they may feel comfortable moving to in the last phases of their life, based on the quality of HIV care that they know they might receive in different places. This usually means choosing to stay based in more urban areas, where HIV care is more accessible and of a higher standard, rather than opting for quieter, rural living, which they might otherwise have chosen.

Participants also shared that their experiences with GPs in the past have not instilled confidence in primary care to have the necessary knowledge about drug interactions for HIV and other conditions. Some individuals shared that their loved ones are doing the research for them to ensure that prescribed drugs are safe to take alongside their HIV medication. This concern extends to entering the care system, if needed, and a worry around whether care home staff will have knowledge of HIV and medications that participants might need for this and other co-morbidities and conditions. The group suggested that GPs need to work more closely with HIV consultants and clinicians for older people, with increasing numbers of conditions to manage, and decreasing levels of trust in GPs. This is also important as mobility becomes more difficult and travelling between healthcare settings may become less possible for some individuals. Medication delivery services were also discussed, with many participants sharing that these are unreliable and inconsistent, meaning that those who are less mobile may not have guaranteed access to their treatment.

Some participants feel they have learned how to 'play the system' when it comes to accessing their medication and the support they need. It was suggested that a form of mentoring from older people living with HIV to those younger or newly diagnosed could be helpful, to learn some of these 'tricks of the trade'.

Experiences of stigma

Older people felt that in general, their group has moved past feelings of shame around their HIV status and that their experiences of self-stigma are minimal. Participants shared that their approach has become different as they have become older, and in terms of sharing their status, this is done on a 'need to know' basis – among loved ones and relevant healthcare staff. Overall, the group was not concerned about sharing beyond this and have made peace with the fact that they are living with HIV – most of our participants were diagnosed a long time ago and have therefore had time to come to terms with their status; this may not be the case for older people who may have been diagnosed more recently. Overall, perspectives from our participants align with data from the 2022 Positive Voices survey, which show that it is more common for older people not to share their status with anyone and may also contribute to why life satisfaction scores seemed to increase with age.

Despite this, experiences of stigma in the workplace and healthcare settings were still shared by many. A number of participants reported leaving jobs due to ignorance about HIV among their respective employers. Experiences with GPs and dentists were varied, and participants expressed frustration with the fact that the seniority of staff that see them at their HIV clinic has seemed to decrease over time. They shared that initially they would always be seen by a consultant, who would be the same every visit, and now many are seen by nurses who will be different each time. This means that rapport and trust is more difficult to build, and for some, has led to stigmatising experiences due to a lack of relationship between patient and healthcare staff. Further, participants shared that when invited for vaccines (such as for COVID-19) due to HIV being their 'underlying health condition' deeming them eligible, they have been questioned in front of others and in waiting rooms, creating an uncomfortable situation where they have had to share their status against their will.

Mental health

Data from the 2022 Positive Voices survey show that older people report lower levels of loneliness. Participants felt that as they have become older, they've become less social, meaning they need less interaction and don't feel lonely as a result. Others suggested that this may be because they have more interaction with the care system and have regular contact with people through this.

When asked whether social events with other people living with HIV were of interest to them, the older age group felt that a balance between networking with those living with HIV, and those who are not, would be helpful. Participants suggested that groups for older people should be centred around activities – such as wine tasting or film club – rather than talking solely about their HIV status. Many felt that they had 'been there, done that', and that they would rather focus on enjoyment in life, needing less support around their HIV specifically. Again, this may be a reflection of living for a long time with diagnosed HIV, and may not be the feelings of an older person who learned of their status more recently.

Reflections on how to improve quality of life for people aged 50 and over

- Seeing people of influence speak up about HIV and U=U would be useful for older people
- Ensure that people can access high quality care wherever they live. Geographical variation is a real concern – especially for people who will be entering social care sector
- Stronger relationships between HIV clinics and GPs is more important as longer-term conditions and co-morbidities become more common and trust in GPs remains low
- Medication delivery services are inconsistent, which is difficult when mobility becomes an issue
- Mentoring from older people to younger and newly diagnosed people living with HIV could be helpful in learning how to navigate the UK health system and overcome stigma

National AIDS Trust (NAT) is the UK's HIV rights charity. For more on the issues surrounding HIV in the UK, what's being done to change them and how you can get involved, visit: www.nat.org.uk

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Positively UK provides peer-led support, advocacy and information to anyone living with HIV to manage any aspect of their diagnosis, care and managing life with HIV. To find out more visit: www.positivelyuk.org

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