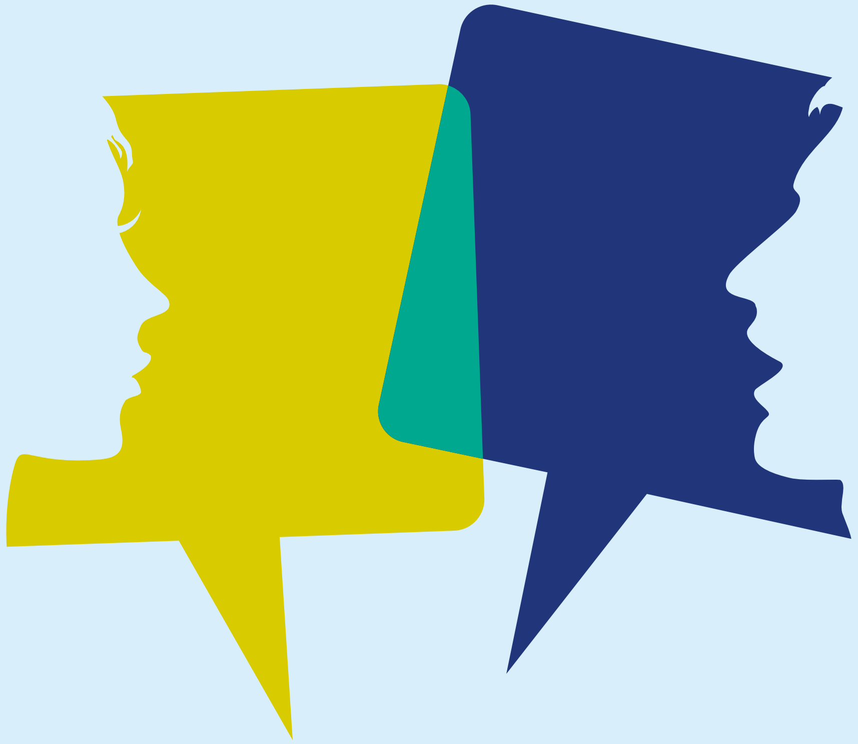
Terrence
Higgins
Trust

“I don’t want other people to write my history for me”: exploring what’s important to people living with HIV towards the end of their lives.

A co-produced
research project from
Terrence Higgins Trust
and Marie Curie

Marie
Curie



Acknowledgments

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UCL

Foreword from Matthew Reed

CEO Marie Curie

Everyone deserves the best possible end of life experience.

For too many people in need of palliative and end of life care and their families, the reality falls far short of this.

Too often, it is those who have been most likely to experience health inequalities throughout their lives who are most at risk of a poor end of life experience.

Listening to the experiences of older people living with HIV, who may continue to face stigma due to their HIV status, their sexuality or their ethnic origin, and how these intersect is vital to understanding these inequalities and how they can impact on accessing palliative and end of life care.

This report, a collaboration between Marie Curie and Terrence Higgins Trust and funded through Marie Curie's Internal Small Research Grant, brings together the experiences of a group of older people living with HIV in Brighton and Hove, who attended the No Barriers Here© workshops in combination with the views of people living with HIV across the UK who responded to the online questionnaire.

The report highlights the multiple challenges that people living with HIV face with regards to palliative and end of life care and recommends that whilst there has been a growing emphasis on ageing well for people living with HIV, it is imperative that this includes care towards the very end of life.

As the UK's leader in end of life experience, Marie Curie is committed to investing in high quality research evidence and engaging with decision makers to better understand and address inequalities and inequities in palliative and end of life care. Everyone deserves the best possible end of life experience: taking an equity by design approach and improving access to and experience of palliative and end of life care for minoritised groups and individuals will result in better care for all. We look forward to working with all of you to make this a reality.

Foreword from Richard Angell OBE

CEO Terrence Higgins Trust

It is remarkable to think that when Terry Higgins died in 1982 – the first named person in the UK to die of an AIDS-related illness – the virus attacking his immune system did not even have a name, let alone a test, care or any treatment. As we mark what would have been his 80th birthday this 4 July, it's amazing to reflect on how much has changed. HIV is a long-term condition, and people taking their medication have a normal life expectancy – many already living to 80.

Those on treatment can have sex without a condom and not pass on the virus, and the majority of people living with HIV are now over 50 years old. Co-morbidities are a reality for all of us in later life, but HIV brings its own complexities.

Those who lived with years of untreated virus are more likely to have additional challenges, and those who experienced the early drugs might still be living with the effects. The relationship between HIV and poor mental health, substance misuse, and loneliness and poverty, compounds it all. In an epidemic exacerbated by health inequalities, you can see in older age history repeating itself.

In a sector built on end of life care, it's amazing how much 'dying well' has fallen from our lexicon since treatment became effective in the late 90s. Some of this is understandable when fighting the stigmatising association of HIV and AIDS with death and a different cohort living with HIV. But the success of treatment and a very different end of life journey must be navigated. This timely collaboration with Marie Curie, UK leader in end of life experience, has put people living with HIV back in the driving seat on a conversation about how to die well.

The trepidation expressed in the research, its findings and the testimony of people ageing with HIV show the crossroads we are at.

For both LGBT+ communities and people of Black African ethnicity, the two demographics most impacted by HIV, ageing, entering care homes and end of life care can be fraught with homophobia, biphobia, transphobia and racism. Added to this, it is custom for care facilities to take your drugs from you – stripping you of your agency in this life-saving daily ritual – and commit that medication to a communal cupboard, with your anonymity gone too. Both are done to ensure maximum adherence but having the word 'dolutegravir' next to your name is not radically different from the clipboard at the end of the bed saying 'homosexual, at risk of AIDS' as one of our participants recalls. We all know confidentiality is tough to maintain in any kind of live-in institution.

HIV stigma continues to have a significant impact on the healthcare, relationships, family life, work, and social interactions of many people living with HIV. Many people living with HIV face discrimination or fear of being judged, which can prevent them from seeking healthcare. In fact, one in thirteen people living with HIV has avoided medical treatment or care because of stigma*.

The findings in this report detail how important retaining a sense of self at the end of life is for people living with HIV. This innovative piece of research created a safe space for people to explore their thoughts and feelings about dying and their end of life care, and in return they provided us with a current picture of what matters to and concerns people living with HIV regarding their end of life planning and care.

We must build upon this work and ensure that providers of end of life support and care are attuned to the needs of people living with HIV and ensure that no one experiences stigma or discrimination as they approach the end of their lives.

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*The Positive Voices survey 2022, January 2022, UKHSA

Contents

Executive Summary

Previous research tells us that some people in the UK are less able to receive the care that they may need when they are terminally ill or dying. We know that people living in poverty, people with diagnoses other than cancer, people who are from minority ethnic backgrounds and people who are gay/bisexual or transgender are included in this. There is little research undertaken to understand the specific experiences of older people who are living with HIV with regards to palliative care.

The population of people living with HIV is ageing and demand for palliative and end of life care support for this group is increasing. There is a growing emphasis on ageing well for people living with HIV, but less focus on care towards the very end of life. HIV-related stigma and discrimination is likely to have been experienced by many people living with HIV. In particular, older people who may have experienced discrimination and poor access to care in the 1980s and 1990s may therefore be concerned about planning for and accessing end of life services when they may need them.

This report draws on a collaborative and co-produced research project conducted by Marie Curie and Terrence Higgins Trust. Using an equity-oriented, arts-based method, and an online survey, people living with HIV explored and considered what might be important for them towards the end of life.

Three key themes were identified through the project which provide useful insights for the future of palliative care for this population. These themes included how lifelong, intersecting experiences of discrimination negatively impact experiences of healthcare and ultimately upon access to care and support towards the end of life, the range of priorities for people towards the end of life, and the importance of maintaining a sense of self through life and into death.

It is imperative that the learnings from this co-produced work are taken forward and implemented in both specialist HIV and generalist services to tackle the inequity that is evident in experiences faced by people living with HIV, throughout and towards the end of their lives.

Background

Access to palliative care is not equitable, both in the UK and internationally. People from marginalised communities experience wider societal disadvantage and are disproportionately represented among the one in four dying people across the UK who are unable to access the palliative and end of life care they need (Allsop et al., 2018). This inequity takes many forms.

For example, with regards to access to hospice care, a recent review found that people with non-cancer diagnoses, people aged over 85, people from minoritised ethnic backgrounds, and those living in rural or deprived areas are under-represented in hospice populations (Tobin et al., 2022).

Many intersecting factors influence access and equity with regards to palliative and end of life care support. Evidence tells us that some communities report lower awareness of palliative and end of life care (Bazaragan et al., 2021), while a lack of trust, and previous negative experiences within health care systems can also contribute to inequity. For example, people from LGBTQ communities are more likely to delay seeking health care support than heterosexual people (Pfister, 2023), meaning their illnesses may be at a more advanced stage when presenting to services, limiting opportunities for the early introduction of palliative care.

Whilst medical advances have meant that HIV is now often undetectable in the blood, the social impact of living with HIV remains a major issue (Flint, Gunsche and Burns, 2022). This is in part due to the ongoing stigma related to HIV in society combined with intersecting stigmas such as being gay or migrant (Walker, 2019).

Through the introduction of antiretroviral therapy (ART), treatment can now reduce a person's viral load to undetectable levels meaning they can maintain a healthy immune system and not pass on the virus. Where access to ART is high, as in the UK, we can see that the number of people living with HIV aged over 50, and the number of people with comorbidities, is increasing.

Access to palliative care has been shown to be beneficial for people living with HIV (Harding et al., 2005). Indeed, the World Health Organisation and UNAIDS recognise palliative care as an essential component of HIV care throughout the course of the condition.

There is a growing body of evidence regarding the experiences and needs of people living with HIV with regards to palliative care (Harding, 2018; Harding et al., 2021). One aspect of this is advance care planning, which is a patient-centred approach to ensuring that an individual's wishes and preferences with regards to their care towards the end of their life are known and respected. A recent systematic review identified few studies that considered interventions specifically for people living with HIV (Meyers, 2024). Other studies have noted that the completion of advanced directives is low among people living with HIV (Barocas et al., 2014).

With a growing population of people living with HIV who are ageing and increasing recognition of the role of palliative care within treatment for people living with HIV, it is important that we explore particular experiences of planning for palliative and end of life care and of accessing services from people living with HIV. We need to ensure that we can support people living and dying as best we can, and in their preferred way whatever their circumstances (Collier and Chapman, 2023).

On co-production

Marie Curie's Community Engagement, Involvement and Development Strategy recognised the importance of working in partnership with our communities to innovate and develop new services that are informed by evidence and insight of people with lived experience.

"Placing the voice and experience of people and communities at the heart of their work will help partners to understand what people need, what is working, what can be improved and how they can work together to deliver what matters to the people they serve." (Thorsten-Woll et al., 2021)

Patient and community-informed research is shown to "yield more inclusive research results that can be accessed and implemented sooner, and in more universal, useable, and equitable ways." (Paolucci A et al., 2022)

Aims of the project

- To enable older people living with HIV to explore and consider what is important for them at the end of life and start planning ahead.
- To enable service providers to understand the need to develop innovative, collaborative and inclusive services in partnership with diverse communities through listening to and understanding the experiences of older people living with HIV.

What did we do?

This collaborative project had four phases, as outlined below.

Phase 1:
Building a relationship and getting set up

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Phase 2:
No Barrierrs Here© workshop

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Phase 3:
Developing and delivering an online survey

⇩

Phase 4:
Summarising the findings and agreeing recommendations

Phase 1:
Building relationships

Co-production was integral to this project, in recognition of the benefits of bringing together the voices of lived experience, expertise in supporting people living with HIV, and expertise in palliative and end of life care delivery and research.

At the start of our joint working relationship, Marie Curie and Terrence Higgins Trust decided to jointly deliver several Life Café sessions at the Terrence Higgins Trust offices in Brighton. A Life Café is a group session in which a kit containing a variety of items, activities and resources, is shared with participants and discussed to gather stories, experiences and ideas about life, death and dying (Fisher, Craig and Chamberlain, 2019). The Marie Curie Community Engagement Team have used the Life Café approach to open conversations with different groups in community settings, but prior to this work they hadn't been used with people living with HIV. The events were very well received and provided reassurance for both Marie Curie and Terrence Higgins Trust about the acceptability of talking about death and dying among people living with HIV and formed a strong basis from which this research project could grow.

Setting up the project

Following the Life Café events, a project Steering Group was established. This was vitally important in terms of ensuring the language and approach used throughout were sensitive and appropriate.

Steering Group members included people with lived experience (two of whom were involved in the Life Café events or were identified through Terrence Higgins Trust staff), the Principal Clinical Psychologist from Brighton and Hove HIV and Sexual Health Service, and Community Engagement and Research staff from Marie Curie.

The Steering Group met regularly online, and also in person and together developed a successful research funding application for the Marie Curie Small grants scheme. Ethical approval was obtained from the UCL Research Ethics Committee ref: 6202/012 approval granted on 27 March 2024.

After funding was received, two Terrence Higgins Trust staff and six Marie Curie staff were trained in the No Barriers Here© methodology to equip them to deliver the qualitative workshops.

Members of the Steering Group, Marie Curie and Terrence Higgins Trust staff and the No Barriers Here© team after the facilitator training.

Phase 2: No Barriers Here© workshops

A participant in Workshop 2

The No Barriers Here© approach was utilised in the workshop. No Barriers Here© was developed in 2019 by The Mary Stevens Hospice, Dudley Voices for Choice and an Arts Psychotherapist as a co-produced project to improve advance care planning and access to palliative and end of life care for people with learning disabilities. The team has since worked co-productively with and alongside communities who experience health inequalities and structural vulnerability to address systematic barriers. As they describe;

> *“Arts-based methods have been used to amplify the voices of marginalised groups, people and communities throughout history. Art-making and creativity are both innately human instincts and can act as great levellers. In recent years, developments in neuroscience and understandings of the impact of trauma have highlighted the need for less verbal approaches for some groups and communities. When used with people and groups who experience similar exclusion, these methods have found to be an excellent way to have deeper, safer, broader, more meaningful conversations about care at the end of life.”*

No Barriers Here© is an equity-oriented, arts-based approach to advance care planning, aimed at people, groups and communities who may be marginalised in healthcare. It uses co-production to ensure that it is accessible, challenges inequity and is strongly influenced by the lived experience of people and communities.
The Steering Group determined this approach was a good fit for working with older people living with HIV.

Recruitment

Workshop participants were older adults who were living with HIV. Participants were recruited by Terrence Higgins Trust through their current and previous service users and through their partner organisation at Lunch Positive. Participants were provided with £15 an hour for attending, in recognition of the time they spent taking part in the workshops. At the beginning of each cohort, the main details from the information sheet were discussed and written consent to participate was obtained from those who hadn't completed the online consent form.

Data collection

No Barriers Here© uses as a series of three consecutive workshops, each held a week apart, which allow for the complexities of planning for end of life to be explored, trust to be built and for participants to have the space to explore and work out how they think and feel before being asked to share.

Each workshop is designed to explore a different aspect of the advance care planning process. These were held across 3 weeks.

Workshop 1	Who am I? What is important to me?
Workshop 1	Who are the important people in my life who can help me make decisions about my care? Where would I like to be cared for? What are the most important things about my future care? What are my funeral plans?
Workshop 3	What would I like my legacy to be? What has been important in my life? How would I like to be remembered?

Two Terrence Higgins Trust staff and two Marie Curie staff from the Steering Group facilitated the workshops in Brighton between April and July 2024. Three cohorts of participants were recruited. Each group ran for three consecutive weeks. Two cohorts completed the workshops at the offices of Terrence Higgins Trust and one cohort was held at the venue used by Lunch Positive.

Each session was recorded and the notes transcribed. All of the artwork created was photographed, with participants' consent. Steering Group meetings were used as an opportunity for facilitators to reflect discussions from the workshops and for the group to reflect on any adaptations that may be needed for future sessions.

Support for participants

The Steering Group recognised that talking about these issues may be upsetting for some people. Therefore, a comprehensive information sheet and an online consent form were provided to participants prior to the first workshop, which outlined what the project was about, and what participation would involve.

A Clinical Psychologist was present throughout the workshops for debriefing or follow up. At the end of each workshop, information about Marie Curie's Information and Support Service was provided. Each participant was contacted by Terrence Higgins Trust staff in between weekly workshops and after completion of all three workshops to check in and provide additional support and resources, if required. This was followed up by final email listing a range of support organisations locally and nationally that participants could access.

Analysis

Anonymised transcripts from the workshops were analysed using Reflexive Thematic Analysis (Braun & Clarke, 2019) by members of the Steering Group. All transcripts were read and re-read by Steering Group members from Marie Curie, and key codes (i.e., important pieces of information) and then themes were identified.

The Steering Group met in person for a full day analysis workshop in which all the transcripts and artwork from the workshops were reviewed and the codes and themes generated by the Marie Curie Team were reviewed. This resulted in a list of themes which was then refined iteratively by returning to the transcripts and through further discussion within online Steering Group meetings, which is described in the results section.

Phase 3: Developing and delivering an online survey

The themes identified from the workshops were used to inform the content of an online survey. The aim of this survey was to explore the views and experiences of a wider sample of people living with HIV with regards to palliative care and health care in general. We also wanted to explore whether the themes identified in the workshops resonated with a wider sample of people living with HIV.

Developing the survey

Informed by themes identified in the workshops, and previous research around awareness of palliative care (Zimmerman et al., 2024) and attitudes to dying and death among the general population (Goss et al, 2024), a survey was co-designed by the Steering Group.

The survey explored the following:

- knowledge of palliative care
- experiences of palliative care
- what would be most important to them regarding their care towards the end of life
- perceptions of stigma in different health care settings
- where respondents would feel comfortable accessing information about palliative and end of life care
- demographic information including; age, gender, gender identity, ethnicity, sexuality, degree of financial security and whereabouts in the UK they lived.

The survey was created in MS Forms and consisted of mainly closed questions, with some optional free text boxes for people to elaborate on answers given or share any further thoughts about palliative care. It was then piloted with a small group of people living with HIV, who had also participated in the workshops.

Data collection

The online survey was live from September to October 2024 and took around 10 minutes to complete. Links to the online survey were shared through Marie Curie Community Networks in the South East, as well as through the networks of the Community Engagement Managers across the UK. Terrence Higgins Trust shared it through their partner organisations supporting people living with HIV in the South East. Both organisations shared it through our social media platforms.

Data analysis

Data gathered through the online surveys were described using descriptive statistics. Responses to open text questions were analysed using reflective thematic analysis.

Phase 4: Summarising the findings and agreeing recommendations

Bringing together the evidence

The Steering Group met for an additional analysis session in which they reviewed the findings from the online survey and reflected on how those findings related to the themes identified through the workshops.

This section of the report outlines the characteristics of participants across both phases of the project and then describes the key themes from the workshops and brings in relevant evidence from the online survey. Examples of the artwork produced as part of the workshop which supports each theme are also included.

Characteristics of the samples

Workshop participants

Twenty-seven people living with HIV were recruited to phase 1. Consistent engagement was observed with all participants attending all three sessions.
The demographic characteristics of workshop participants can be found in Table 1, Appendix 1.

The majority of workshop participants were male (n= 24, 89%). Just over a quarter of the sample were gay men (n=7 (26%)). The age of workshop attendees ranged from 35 to 84, with the majority being over 55.

Survey participants

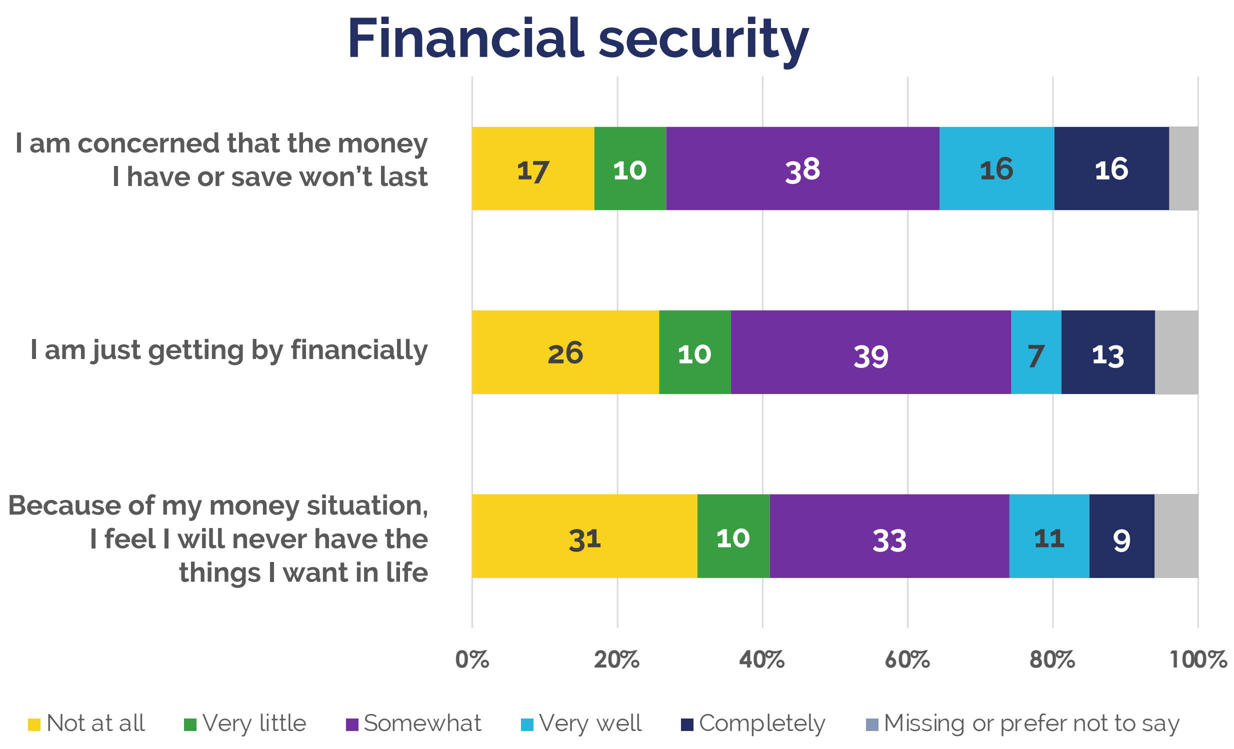
In total, 85 eligible responses to the survey were received. These were from people living with HIV from across the UK. Five responses were excluded as the respondent did not identity as living with HIV. Participant characteristics are given in Table 2, Appendix 1, with key findings outlined below.

The mean age of survey participants was 57.6 years, ranging from 36 to 79 years. Over three-quarters identified as male (77.8%), while 14.4% identified as female, and 2.2% as non-binary. The majority of respondents (92.2%) reported their gender was the same as assigned at birth. The majority of respondents (70.0%) identified as a gay man. 13.3% identified as heterosexual, 5.6% bisexual, and a small percentage identified as “other” (1.1%). Most respondents identified as white (82.2%), with smaller proportions identifying as Black (5.6%), mixed (3.3%), Asian (1.1%), or “other” (1.1%).

Around three-quarters of respondents (74.4%) reported living in the South East of England, with smaller proportions in London (6.7%), the South West (2.2%), the East of England (2.2%), Yorkshire & Humberside (2.2%), the West Midlands (1.1%), Wales (1.1%), and Scotland (3.3%).

Financial security

Financial security was not assessed for workshop participants, but a high level of financial insecurity was observed among survey respondents (Table 2, Appendix 1). Just under a third (32.2%) of respondents reported a total annual household income of less than £20,000, with a further 10% reporting a total household income of £20,000 to £29,999. 13.3% of respondents either preferred not to say or did not answer the question. Less than a third of respondents described making plans for their financial future (26.7%), despite the mean age of respondents being 57.6 years. Indeed, financial security was an area of concern, with only 18.9% of respondents reporting that the statement "I am secure in my financial future" described them "Very well" or "Completely." Just over a quarter (26.7%) felt this described them "Very little" or "Not at all" (Table 3, Appendix 1). Figure 1 outlines other aspects of financial insecurity that were reported in the sample (all figures are percentages).



All numbers expressed as percentages (%)

Figure 1. Responses to the question, "How well does each of the statements describe you?"

Financial insecurity has been associated with poorer experiences towards end of life challenges and so is of particular note here.

Knowledge of and experience of palliative care

The survey asked participants about their experiences with accessing palliative care, either for themselves or others. Only a small number of respondents (n=3) had accessed palliative care themselves, 42 respondents indicated that someone close to them (a friend or family member) had accessed palliative care (11 of those were people who were living with HIV, 31 people were living with a diagnosis/es other the HIV), 2 respondents were not sure whether they or someone close to them had accessed palliative care, and 64 had no experience in accessing palliative care either for themselves or someone close to them.

Despite limited interactions with palliative care services, the majority of respondents (58.9%) reported that they knew what palliative care was and could explain it to someone else. A third of respondents (33.3%) reported that they knew a small amount about palliative care, and around 7% respondents reported knowing very little or nothing about palliative care.

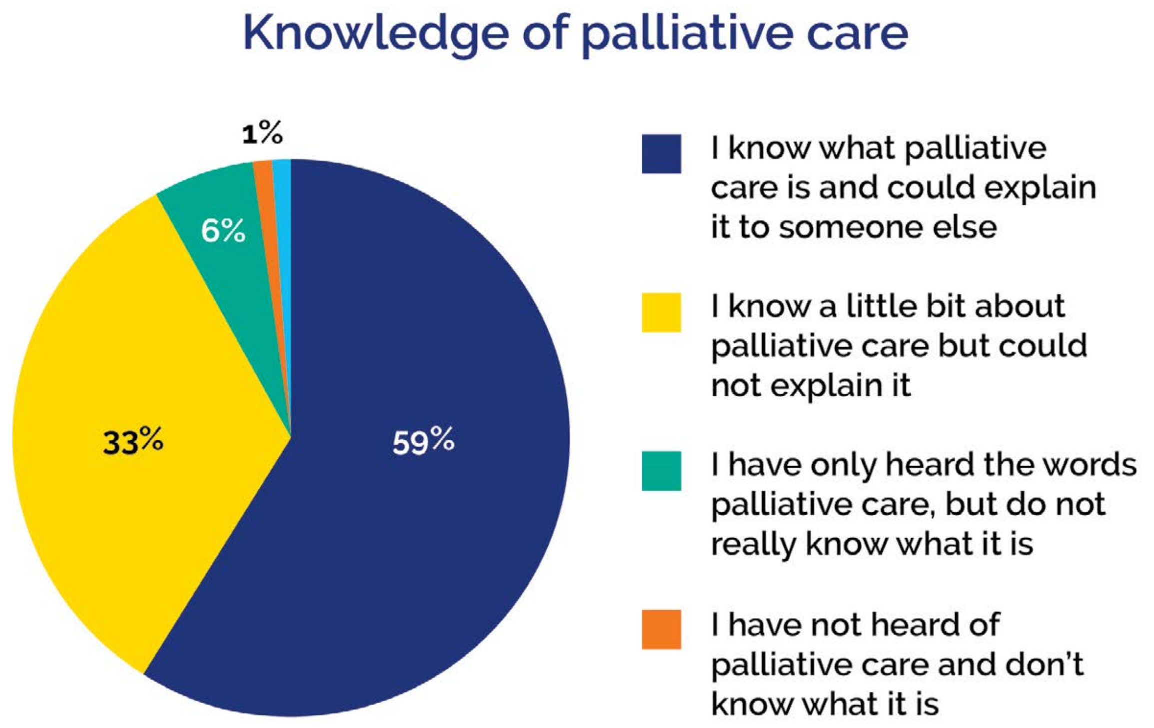


Figure 2. Responses to the question, "How would you describe your level of knowledge about palliative care?"

Summary of themes from the project

The following themes and subthemes were identified through the project:

Theme 1:

Lifelong, intersecting discrimination as a barrier to palliative care services

- Negative experiences, stigma and mistrust

Theme 2:

Priorities for end of life

- Maintaining identity
- To not be alone or isolated
- For what happens to them after death to be as expressed in life

Theme 3:

Maintaining sense of self through to death

- Not having to hide my identity
- Sustaining hobbies and interests

Theme 1: Lifelong, intersecting discrimination as a barrier to palliative care services

Facing Discrimination.

Negative experiences, stigma and mistrust

In the workshops many people living with HIV described worries about accessing palliative and end of life care due to the stigma they had faced throughout their lives. Participants described their experiences of stigma within health care services:

> *They used to put the clipboards on the end of the bed with the temperature charts on it, and they had written across it "homosexual, risk of AIDS" for all to see. And I remember taking it off and ripping it up."*
>
> **(Person living with HIV)**

Experiences of stigma in health care settings were also evident among responses to the survey. Participants reported that their HIV status "Sometimes", "Often", or "Always" negatively affected their experiences of care in GP (40 %), hospital (38.9 %), and dental (43.4 %) settings respectively (Table 5, Appendix 1).

Impact of HIV on experiences of care

"Do you feel that your HIV status has negatively affected your experiences of care in the following settings?"

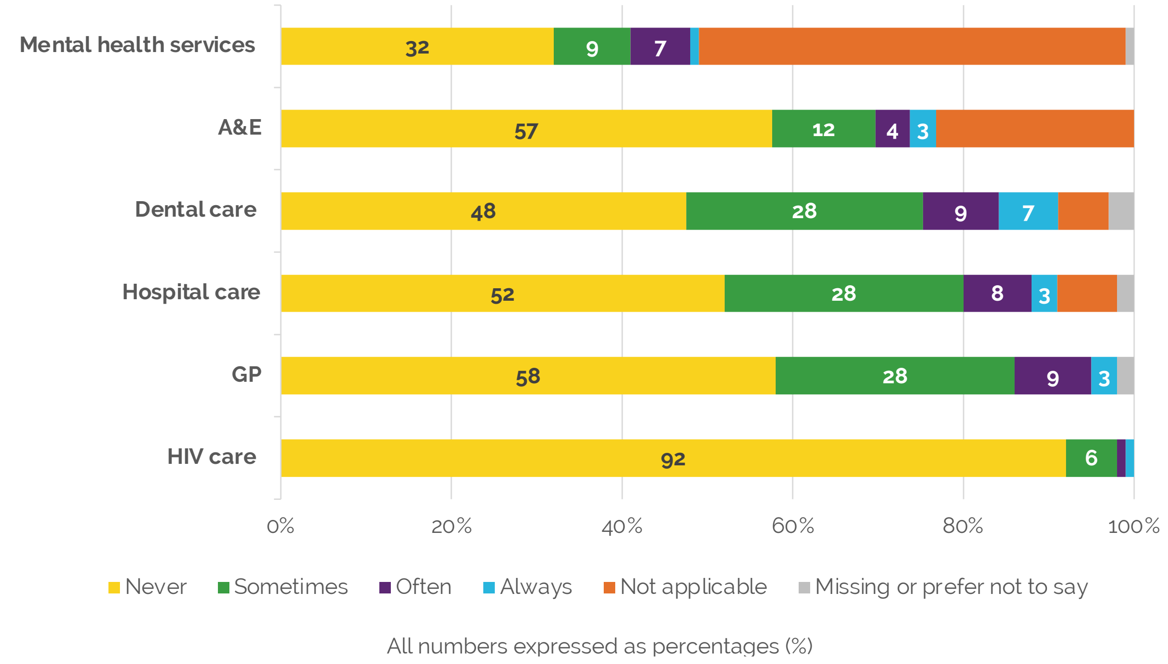


Figure 3. Responses to the question, "Do you feel that your HIV status has negatively affected your experiences of care in the following settings?"

In the workshops, older participants spoke about their negative experiences of living through the HIV crisis in the 1980s and 1990s. They told of traumatic experiences during this period, including severe discrimination and losing many loved ones. Some participants discussed how the high number of deaths has had a lasting impact on their perceptions of end of life care.

> *I lost track of the number of funerals I went to. And that was a dark time in everyone's life because everyone was dying like flies."*
>
> **(Person living with HIV)**

These lifelong, negative experiences (such as seeing their loved ones receive poor care when living and dying with HIV) meant that people living with HIV often said they did not fully trust health care services to have their best interests at heart. They felt fear that they may be discriminated against due to their HIV status, which was reflected in survey responses also.

> *There's certainly a sort of almost paranoia about anything official in healthcare and it's certainly why we had a problem looking after gay men in the hospice."*
>
> **(Person living with HIV – Steering Group)**

In the workshops people living with HIV said that because of this distrust they often don't access palliative care until late in their illness, or when their loved ones were no longer able to support them. In addition, the fear of facing discrimination often resulted in people living with HIV being afraid to disclose their status and/or sexuality within a health care service, even when they were otherwise comfortable with their identity.

> *Even if people feel very comfortable with talking about their status, their sexuality or any lived circumstances, once they became end of life care, all of that disappeared."*
>
> **(Person living with HIV)**

As some people living with HIV did not engage with palliative care services in part due to fear of discrimination, many were not aware of services, treatments and choices available to them at end of life and after death. This was demonstrated through discussion between workshop participants about what could happen to their body after death.

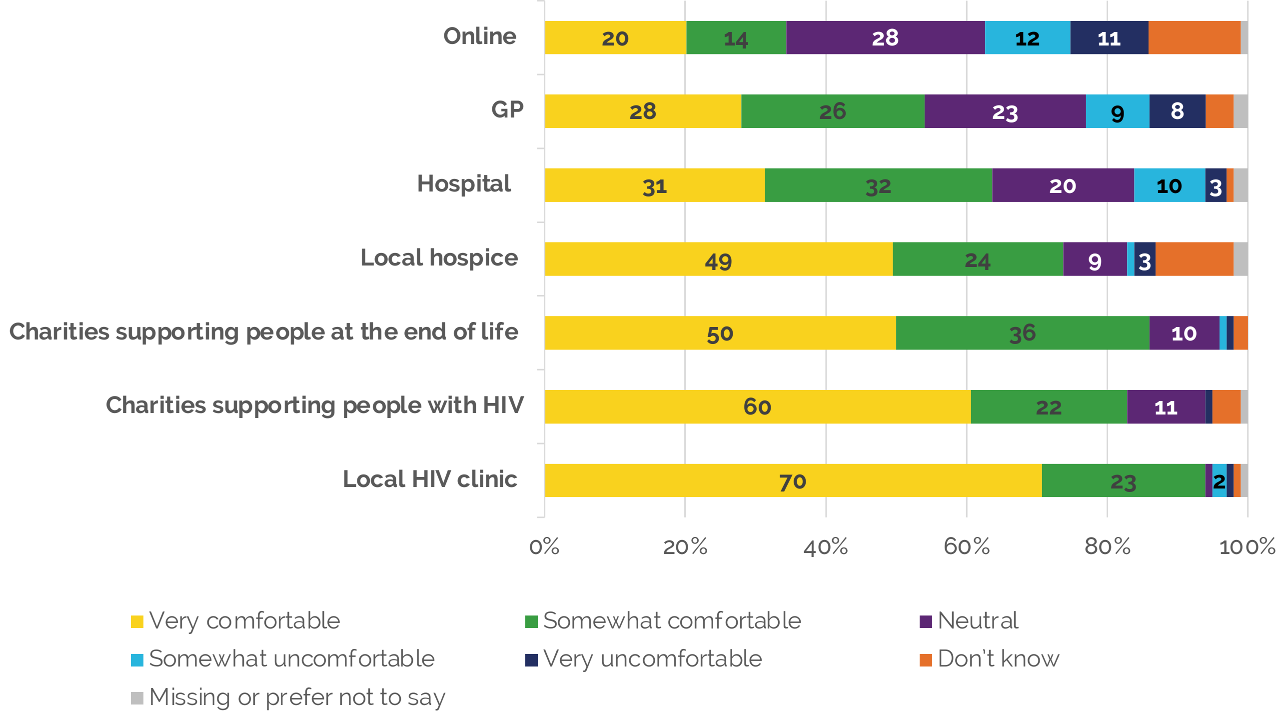
> *Participant A:*
>
> *The HTA [Human Tissue Authority] is where I would like my body to go. We did talk to the person to say it is possible to leave your body for medical science. There are four medical schools in the country, Brighton is one of them, they are open to receiving."*

> *Participant B:*
>
> *I did look into that and was told I couldn't leave my body."*
>
> **(Person living with HIV)**

Given the challenges and anxieties noted among workshop participants with regards to accessing palliative care, a question was included in the survey to inform how best to deliver advice and support about palliative and end of life care in the future. Survey respondents were asked how comfortable they would feel in accessing information about palliative and end of life care from different places, as outlined in Figure 4 and Table 6, Appendix 1.

The importance of trusted places and organisations as sources of information and support was highlighted in survey responses which revealed that local HIV clinics and charities supporting people living with HIV were the two places that they would feel most comfortable accessing information. The survey responses also highlighted an opportunity for charities supporting people at the end of life and local hospices as places in which people living with HIV could feel comfortable accessing information. Interestingly, results indicated that people would feel least comfortable accessing information about palliative and end of life care online.

"How comfortable would you feel about accessing palliative and end of life care advice and support from the following places?"



All numbers expressed as percentages (%)

Figure 4. Responses to the question, "How comfortable would you feel about accessing palliative and end of life care advice and support from the following places?"

Theme 2:
Priorities for end of life

Within the workshops, priorities for care towards the end of life were discussed in various ways and a number of priorities were identified. In the survey, participants were asked how important a number of different priorities that had been identified by the general population were to them (Goss et al., 2024), as well as how important additional priorities identified in the workshops were..

	PADD UK	Our survey
1	Being free of pain and other symptoms	Being in calm atmosphere
2	Maintaining dignity and respect	Being free of pain and other symptoms
3	Feeling safe	Support with psychological wellbeing
4	Being surrounded by loved ones	Maintaining dignity and respect
5	Being involved in decisions about care	Feeling safe
6	Being at home	Being my whole self
7	Being in a calm atmosphere	Being involved in decisions about care
8	If I were not able to decide, then being able to involve my family or people I trust in decisions about my care	If I were not able to decide, then being able to involve my family or people I trust in decisions about my care
9	Having support with practical and/or financial issues	Being surrounded by loved ones
10	Being in my familiar surrounding	Not feeling judged due to my HIV status

Figure 5. Comparison of top 10 priorities for care towards the end of life reported by the PADD UK survey surveying the general population (Goss et al., 2024), and the current study.

Among survey respondents, the priorities that received the highest ratings of importance were being in a calm and peaceful atmosphere, being free of pain and other symptoms, and receiving support for their psychological wellbeing. Priorities identified by workshop participants were also rated as highly important by survey respondents. A full list of priorities explored in the survey can be found in the appendix (Table 7). This section outlines the priorities identified through the workshops, and supporting evidence from the survey.

Acceptance.

Being my whole self.

Maintaining identity

A large majority of survey respondents (97.8%) reported that "being able to be my whole self" was important or very important to them at the end of life. Likewise, 93.4% of respondents felt that "Not feeling judged due to my HIV status" was important or very important.

In the workshops, participants expressed it was important to be able to comfortably be oneself throughout end of life care.

> *They [friend] were out being gay. They were very proud of that for many, many years. And suddenly their fear was by going into hospice that suddenly all those things disappeared. And they weren't treated as that whole person with those identities."*
>
> **(Person living with HIV)**

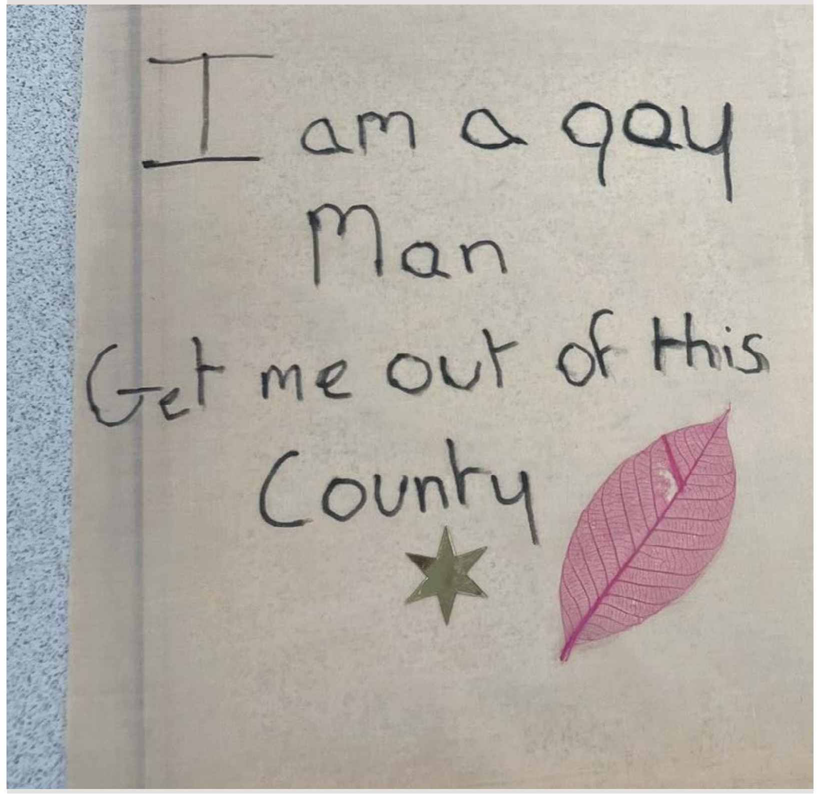
Being able to maintain identity meant that people living with HIV felt they could "write their own narrative", particularly where they felt that their family members may not honour their preferences after death. Maintaining identity throughout the end of life enabled people to "keep their legacy" and formally express preferences.

> *I don't want other people to write my history for me… so many other people who I know who have died, their partners or the family have wiped them out. They don't get to be remembered for who they were rather than someone like gets to choose what their legacy is. And I don't want that."*
>
> **(Person living with HIV)**

Keeping my identity, music and poppers are central to my sexuality.

Importantly, participants felt that it was important to maintain their identity through to the end of their lives, despite the discrimination outlined in the previous theme. People living with HIV often felt they had to fight for the right to openly be themselves throughout their lives, therefore didn't want to retract that if they became unwell.

> *I mean, the last thing you want to do is just spend, spend a large proportion of your life fighting to feel like a normal human being that has a right to live, and then going backwards just in your final moments."*
>
> **(Person living with HIV)**



Being gay and feeling discriminated here.

To not be alone or isolated

Workshop participants discussed that they wanted to be around their loved ones, with recognition that the people who are important to them may change over the life course. Among survey respondents, “being surrounded by loved ones” was rated as either important or very important by 94.5% of the sample.

Some participants spoke about wanting to be around their ‘chosen family’: key people in their lives who may not be biological relatives. Estrangement from family was discussed within the workshops, as shown in the image below. Isolation or loneliness was described by some workshop participants who did not want to feel alone or isolated at the end of their lives.

> *I want people there. I’m very lonely. It would be nice not to die alone.”*
>
> **(Person living with HIV)**

This was supported among survey responses, where 72.2% felt that “not dying alone” was important or very important to them.

One motivation for being around loved ones towards the end of life, was the fear of dying alone and being found days later:

> *My last thing I’d want is to be found several days after I died in my flat or something.”*
>
> **(Person living with HIV)**

Not being alone.

For what happens to them after death to be as expressed in life

Where people living with HIV had expressed preferences for what happens to them after death (such as cremation or funeral arrangements), it was important to them that they were upheld after they died. Many discussed leaving plans with a trusted person, who may not be a family member.

> *I come from a traditional family. I know they will override everything OK. You know, if my husband is still alive, he is going to be the one telling the whole family what you do.”*
>
> **(Person living with HIV)**

Survey respondents echoed this, with 96.7% of respondents rating “If I were not able to decide, then being able to involve my family or people I trust in decisions about my care” as either important or very important.

As outlined above, maintaining identity at the end of life care was a key priority for many people living with HIV. This priority continued after death, as participants discussed how they want to be remembered as who they are in life.

For some, this was about personality traits, such as being strong, independent, caring, or loving. For others, they wanted to be remembered for their contributions in fighting for liberation for LGBTQ+ people and/or people living with HIV.

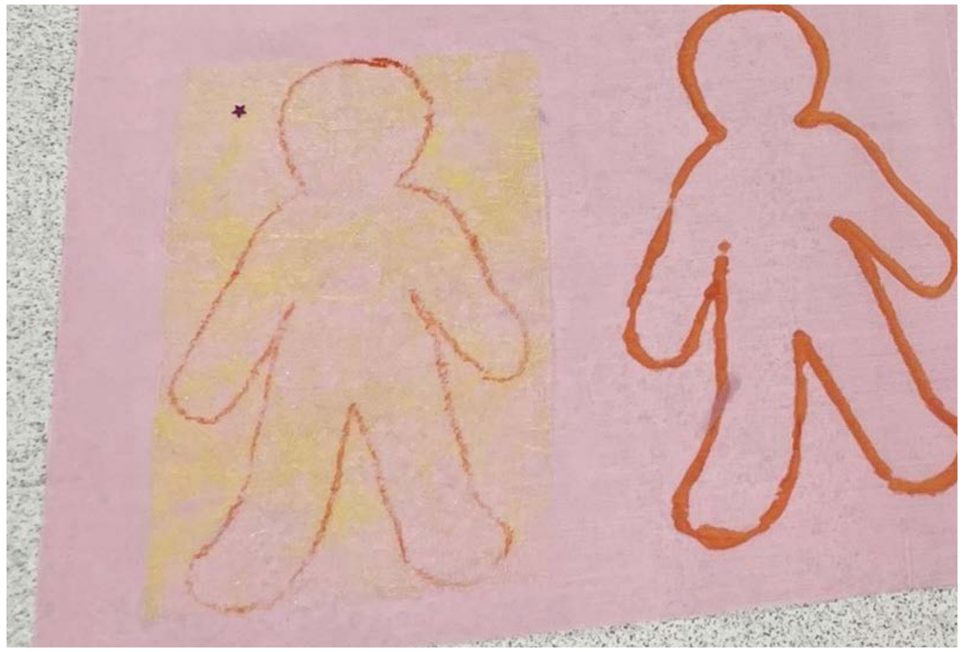
> *I think if there’s anything I want to be remembered for, it would be, I hope, honesty, kindness and egalitarianism. It’s fighting for people who can’t fight for themselves. And that has always been through my life.”*
>
> **(Person living with HIV)**

How I want to be remembered.

Theme 3:

Maintaining sense of self through to death

People living with HIV discussed how it was important for them to maintain their sense of self – including things that are important to them – within their end of life care and through to death. This relates closely to the importance of people feeling comfortable to maintain their identity, including sexuality, spirituality and ethnicity.



Not having to hide my identity.

The vast majority (98.8%) of survey respondents reported that "maintaining dignity and self respect" was important or very important at the end of life. For many, a core part of their sense of self was having challenged the status quo, and having fought for liberation.

> *That was a dark time in everyone's life because everyone was dying like flies as the government took the opportunity to roll back all the few advances we'd made, and it was a real struggle. I was on many a demonstration that turned very nasty with the police."*
>
> **(Person living with HIV)**

Participants also discussed how their loved ones comprised a key part of their sense of self and valued companionship. There was recognition that this companionship came in many forms, including family, friends, community and pets:

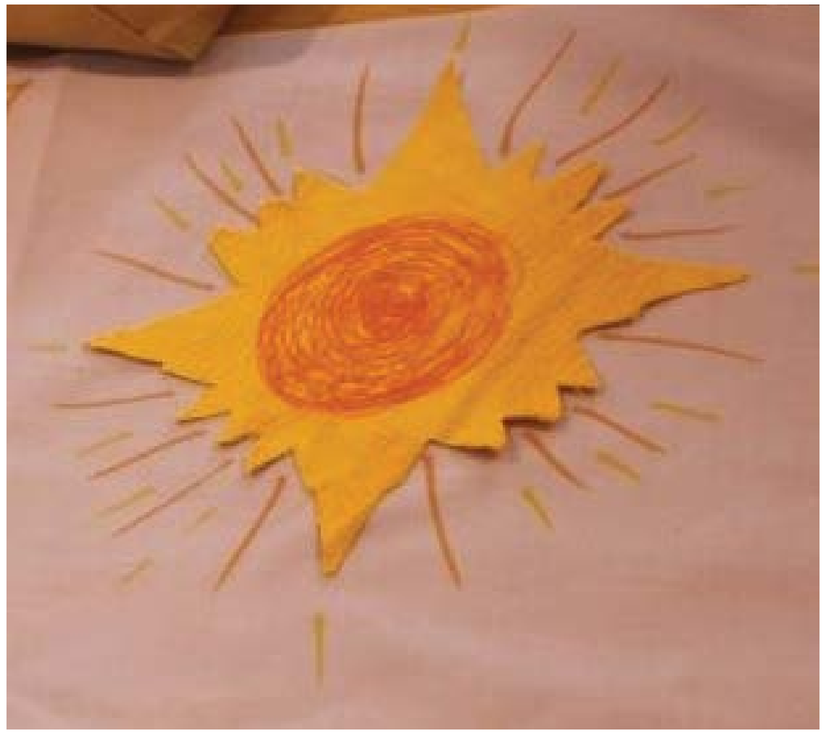
> *The most important thing is my dog. He's kept me going for the past 13 years. He keeps me grounded."*
>
> **(Person living with HIV)**

> *I thought I was a loner. I need connections and my friendships are very important."*
>
> **(Person living with HIV)**

Family, friends and my dog.

The importance of being supported to maintain hobbies and interests throughout end of life care was discussed. For many, this was connecting with the outdoors and nature.

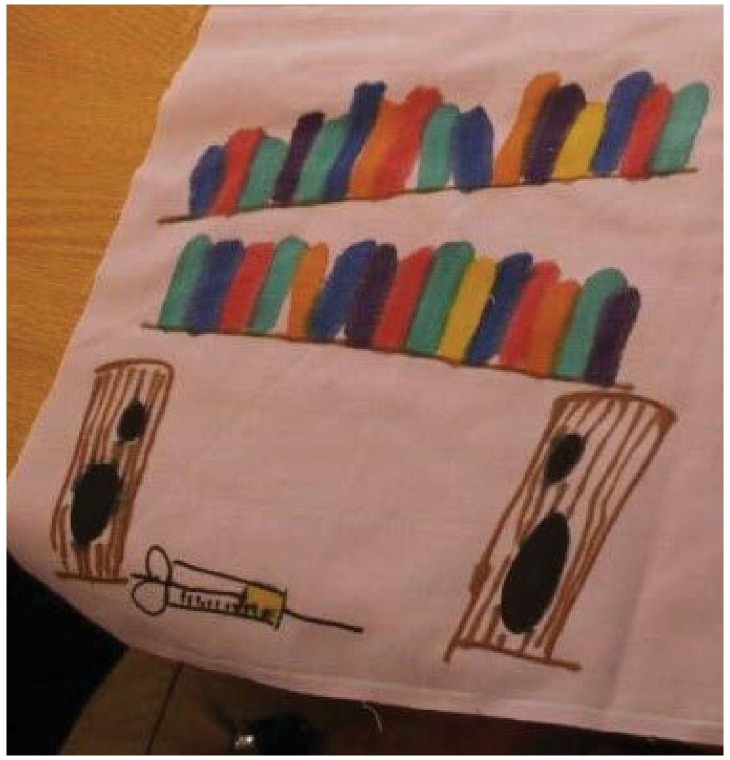
> *I would like to be able to feel the sun on my face, I think. Having particularly having spent for so long, so much, my life living in the sun that feels important to me."*
>
> **(Person living with HIV)**



Being in nature.

For others, it was being enabled to continue to engage in hobbies they enjoy:

> *I wanna have my books. I want to have music or at least audio books if I can't actually physically hold books anymore."*
>
> **(Person living with HIV)**



Reading and music.

Conclusions

The population of people living with HIV is ageing and demand for palliative and end of life care support for this group is increasing. There is a growing emphasis on ageing well for people living with HIV, but less focus on care towards the very end of life. It is imperative that the learnings from this report are taken forward and implemented in both specialist HIV and generalist services more broadly to tackle the inequity that is evident in experiences faced by this group, throughout and towards the end of their lives.

Multiple challenges for people living with HIV with regards to palliative and end of life care have been highlighted in this report, including how lifelong, intersecting experiences of discrimination negatively impact experiences of health care and ultimately upon access to care and support towards the end of life. This echoes previous research outlining how people living with HIV have experienced decades of intersecting stigmatised identities in the context of social isolation, leading to elevated levels of issues like depression, anxiety, and loneliness, all of which may be amplified by ageing (Tamsukhin, 2024).

This work also evidenced elevated levels of financial insecurity among the sample of people living with HIV who responded to the survey. Social deprivation negatively impacts experiences towards the end of life, for a number of interrelated reasons (Bowers, 2022).

Being seen as a whole person until the end of life was one of the issues highlighted as an important consideration for palliative care for this population in this research. Coupled with the impact of mistrust and previous negative experiences when accessing health services, this reflects the importance of providing opportunities for people to consider advance care planning, should they wish to.

There was high engagement by participants throughout the workshops – all participants completed the three workshops. It was evident that some participants had complex lives, yet committed to complete the workshops with us. This may be reflective of a lack of space to have these discussions elsewhere. The time, support and resources to plan ahead, consider, and document preferences, choices and wishes for the future is vital but seems to currently be lacking for people living with HIV (Meyers, 2024). Of the twenty-seven people who took part in the workshops, three immediately asked for the opportunity to complete Advance Care Plans after the workshops and were supported to do.

The engagement of participants may also be related to the use of arts-based approaches such as No Barriers Here©. This approach facilitated a range of inclusive and interactive methods for giving people the space, time and permission to open up conversations about dying, death and bereavement and what matters to them. Many participants and Steering Group members felt that the depth of conversations gained through the method would not have been possible in more traditional approaches.

Reflections

The importance of co-production and partnership working

This project represents the first steps in a new partnership between Terrence Higgins Trust and Marie Curie. Both organisations are deeply committed to reducing inequities in health care access and to working alongside people with lived experience to co-design research and services that have the potential for impact. Building the relationship between the organisations took time, energy and commitment by both organisations, and the success of the project could not have been achieved without this. Future research should not underestimate the importance of, and resource needed for, this essential stage.

The involvement of people with lived experience was paramount. Their guidance, through the Steering Group, ensured that we were flexible in our approach and responded to individual concerns as they arose. In giving their time and personal expertise and experience, project team members with lived experience were able to help shape the development of the research proposal, methodology, analysis and the recommendations.

This partnership-oriented research project has captured important learnings that may inform future design and delivery of palliative and end of life care for people living with HIV. Key messages include:

- Arts-based approaches such as No Barriers Here© offer inclusive methods for opening up conversations about dying, death and bereavement, and what matters to people.
- Partnership working and co-design bring multiple benefits, including making research more accessible, improving the quality of data collected, and enriching interpretations of data generated.
- More work is needed to build on these observations and design services that are accessible and open to everyone, regardless of their diagnoses.

Next steps for this work

Marie Curie and Terrence Higgins Trust have received funding through the Marie Curie Research Impact Fund to co-produce information tailored to the HIV community to help them understand their options, feel included in how they can make decisions and plan for the end of their life and care, as well as highlighting tools and support available to them. It will be available in print and video from the Marie Curie and Terrence Higgins Trust websites and social media. The primary audience for these resources will be people living with HIV, with a secondary audience of those supporting them, including health and social care professionals.

Terrence Higgins Trust have also been included as a Marie Curie partner organisation in the SGN (Vulnerability and Carbon Monoxide Allowance) funded Companions in The Community programme, where underserved communities will be targeted to make sure people with a terminal illness can have a warm and safe home. A Volunteer Services Officer has been appointed for an initial twelve months to deliver this work in the Brighton and Hove area.

Recommendations

Based on the findings of this research, we propose some key recommendations that could contribute to improvements in palliative and end of life care for people living with HIV:

- Organisations providing or commissioning palliative and end of life services should work with their local communities to understand the specific needs of those who face inequity in accessing care, including those living with HIV. They should ensure that these needs are reflected in the way they design and deliver services. It is also important to ensure that data around sexuality, gender, and ethnic origin is adequately and consistently collected and then used to illustrate if the people who use their services are reflective of their local population.
- Organisations providing palliative and end of life care services should proactively work with older people living with HIV in the UK to raise awareness of existing services and sources of support, as well as ensuring that they produce literature and materials that are representative and reflect the needs of their local communities.
- Palliative and end of life care services must increase their understanding about the specific needs of this group, for example in relation to HIV-related medication, potential for higher levels of trauma, the importance of chosen families and ensuring that these individuals are given priority in a patient's care planning, and high levels of financial insecurity. Workforce training and development opportunities must be available.
- Given the lack of awareness amongst the generalist workforce at the moment, it is important that specialist support is available in the meantime to bridge this gap. Therefore, HIV services need to develop pathways to meet the needs of an ageing population with HIV.
- Given the small-scale nature of this research project, it would be beneficial if wider research could be undertaken to capture the voices of people living with HIV more widely. For example, it may be helpful to repeat the Positive Voices survey and include questions around attitudes to death, dying and bereavement.

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Appendices

Table 1: Characteristics of workshop participants

Characteristics	Valid responses only
Age (years)	**N = 27**
35 – 44	1
45 – 54	0
55 – 64	2
65 – 74	4
75 – 84	2
Gender, N (%)	**N = 27**
Male	24 (89%)
Female	3 (11%)
Non-binary	0
Missing or prefer not to say	-
Sexual orientation, N (%)	**N = 27**
Heterosexual	2 (7%)
Gay man	7 (26%)
Bisexual	1 (4%)
Other	
Missing or prefer not to say	17 (63%)
Ethnicity, N (%)	**N = 27**
White	8 (30%)
Black	2 (7%)
Asian	1 (4%)
Mixed	
Other	
Missing or prefer not to say	16 (59%)

Table 2: Characteristics of survey respondents

Characteristics	Valid responses only	Including non-valid responses*
Age (years)	**N = 85**	
Mean (SD)	57.6 (10.6)	-
Median (range)	57.0 (36.0-79.0)	-
Gender, N (%)	**N = 85**	**N = 90**
Male	70 (82.4)	70 (77.8)
Female	13 (15.3)	13 (14.4)
Non-binary	2 (2.4)	2 (2.2)
Missing or prefer not to say	-	5 (5.6)
Gender same as assigned at birth, N (%)	**N = 85**	**N = 90**
Yes	83 (97.6)	83 (92.2)
No	2 (2.4)	2 (2.2)
Missing or prefer not to say	-	5 (5.6)
Sexual orientation, N (%)	**N = 85**	**N = 90**
Heterosexual	12 (14.8)	12 (13.3)
Gay man	63 (77.8)	63 (70.0)
Bisexual	5 (6.2)	5 (5.6)
Other	1 (1.2)	1 (1.1)
Missing or prefer not to say	-	5 (5.6)
Ethnicity, N (%)	**N = 84**	**N = 90**
White	74 (88.1)	74 (82.2)
Black	5 (6.0)	5 (5.6)
Asian	1 (1.2)	1 (1.1)
Mixed	3 (3.6)	3 (3.3)
Other	1 (1.2)	1 (1.1)
Missing or prefer not to say	-	6 (6.7)
Region, N (%)	**N = 84**	**N = 90**
England: South East	67 (79.8)	67 (74.4)
England: London	6 (7.1)	6 (6.7)
England: South West	2 (2.4)	2 (2.2)
England: East	2 (2.4)	2 (2.2)
England: Yorkshire & Humberside	2 (2.4)	2 (2.2)
England: West Midlands	1 (1.2)	1 (1.1)
Wales	1 (1.2)	1 (1.1)
Scotland	3 (3.6)	3 (3.3)
Missing or prefer not to say	-	6 (6.6)
Total annual household income, N (%)	**N = 78**	**N = 90**
Less than £20,000	29 (37.2)	29 (32.2)
£20,000 to £59,999	27 (34.6)	27 (30.0)
£60,000 to £99,999	11 (14.1)	11 (12.2)
Over £100,000	11 (14.1)	11 (12.2)
Missing or prefer not to say	-	12 (13.3)

*Percentage calculated including missing or prefer not to say responses

Table 3: Responses to the question, “How well does this statement describe you or your situation?”

Statement	Completely N (%)	Very well N (%)	Some-what N (%)	Very Little N (%)	Not at all N (%)	Missing or prefer not to say N (%)
I could handle a major unexpected expense	7 (7.8)	12 (13.3)	40 (44.4)	15 (16.7)	12 (13.3)	4 (4.4)
I am making plans for my financial future	14 (15.6)	10 (11.1)	31 (34.4)	16 (17.8)	13 (14.4)	6 (6.7)
I can enjoy life because of the way I’m managing my money	7 (7.8)	23 (25.6)	39 (43.3)	11 (12.2)	4 (4.4)	6 (6.7)
I am secure in my financial future	5 (5.6)	12 (13.3)	30 (33.3)	9 (10.0)	15 (16.7)	19 (21.1)
Because of my money situation, I feel like I will never have the things I want in life	8 (8.9)	10 (11.1)	30 (33.3)	9 (10.0)	28 (31.1)	5 (5.6)
I am just getting by financially	12 (13.3)	6 (6.7)	35 (38.9)	9 (10.0)	23 (25.6)	5 (5.6)
I am concerned that the money I have or will save won’t last	14 (15.6)	14 (15.6)	34 (37.8)	9 (10.0)	15 (16.7)	4 (4.4)

Table 4: Responses to the question, “Below are some statements about palliative care, which of these do you think palliative care provides?”

Statement	Yes N (%)	No N (%)	Not sure N (%)	Missing or prefer not to say N (%)
Palliative care focuses on improving a person’s quality of life	**79** **(87.8)**	6 (6.7)	3 (3.3)	2 (2.2)
People must be in a hospital to receive palliative care	2 (2.2)	**81** **(90.0)**	7 (7.8)	0
Palliative care provides pain management to people living with serious illness	**80** **(88.9)**	4 (4.4)	5 (5.6)	1 (1.1)
Palliative care is a type of care that is only provided to people in the last month of their life	11 (12.2)	**62** **(68.9)**	17 (18.9)	0
Palliative care can help manage a person’s symptoms e.g. nausea or breathlessness	**73** **(81.1)**	5 (5.6)	10 (11.1)	2 (2.2)
Palliative care provides support for a person’s friends or family	**62** **(68.9)**	8 (8.9)	20 (22.2)	0
Palliative care can be provided alongside other curative treatments	**62** **(68.9)**	10 (11.1)	18 (20.0)	0
Palliative care is a type of nursing care provided exclusively by nurses	12 (13.3)	**58** **(64.4)**	18 (20.0)	2 (2.2)
Any person with a serious illness can request access to palliative care	**35** **(38.9)**	19 (21.1)	35 (38.9)	1 (1.1)
Palliative care can be provided at any stage of an illness	**26** **(28.9)**	34 (37.8)	30 (33.3)	0

Table 5: Responses to the question, "Do you feel that your HIV status has negatively affected your experiences of care in the following settings?"

	Never N (%)	Sometimes N (%)	Often N (%)	Always N (%)	Not applicable N (%)	Missing or prefer not to say N (%)
HIV care	83 (92.2)	5 (5.6)	1 (1.1)	1 (1.1)	0	0
GP	52 (57.8)	25 (27.8)	8 (8.9)	3 (3.3)	0	2 (2.2)
Hospital care	47 (52.2)	25 (27.8)	7 (7.8)	3 (3.3)	6 (6.7)	2 (2.2)
Dental care	43 (47.8)	25 (27.8)	8 (8.9)	6 (6.7)	5 (5.6)	3 (3.3)
A&E	51 (56.7)	11 (12.2)	4 (4.4)	3 (3.3)	21 (23.3)	0
Mental health services	29 (32.2)	8 (8.9)	6 (6.7)	1 (1.1)	45 (50.0)	1 (1.1)

Table 6: Responses to the question, "How comfortable would you feel about accessing palliative and end of life care advice and support from the following places?"

	Very comfortable N (%)	Somewhat comfortable N (%)	Neutral N (%)	Somewhat uncomfortable N (%)	Very uncomfortable N (%)	Don't know N (%)	Missing or prefer not to say N (%)
GP	25 (27.8)	23 (25.6)	21 (23.3)	8 (8.9)	7 (7.8)	4 (4.4)	2 (2.2)
Local HIV clinic	63 (70.0)	21 (23.3)	1 (1.1)	2 (2.2)	1 (1.1)	1 (1.1)	1 (1.1)
Charities supporting people at the end of life	45 (50.0)	32 (35.6)	9 (10.0)	1 (1.1)	1 (1.1)	2 (2.2)	0
Local hospice	44 (48.9)	22 (24.4)	8 (8.9)	1 (1.1)	3 (3.3)	10 (11.1)	2 (2.2)
Charities supporting people with HIV	54 (60.0)	20 (22.2)	10 (11.1)	0	1 (1.1)	4 (4.4)	1 (1.1)
Hospital	28 (31.1)	29 (32.2)	18 (20.0)	9 (10.0)	3 (3.3)	1 (1.1)	2 (2.2)
Online	18 (20.0)	13 (14.4)	25 (27.8)	11 (12.2)	10 (11.1)	12 (13.3)	1 (1.1)

Table 7: What would be important to you at the end of life

Thinking about the care and support you would like to receive towards the end of your life, would any of the following be important to you? (treated with respect, treated as a whole person, not to be judged, no pain – etc)

Padd items	Not at all important N (%)	Important N (%)	Very Important N (%)	Don't know N (%)	Missing or prefer not to say N (%)
Not feeling judged due to my HIV status	6 (6.7)	16 (17.8)	68 (75.6)	0	0
Being able to be my whole self	0	17 (18.9)	71 (78.9)	1 (1.1)	1 (1.1)
Being surrounded by loved ones	3 (3.3)	26 (28.9)	59 (65.6)	2 (2.2)	0
Being surrounded by personal things/pets	9 (10.0)	32 (35.6)	44 (48.9)	4 (4.4)	1 (1.1)
Being surrounded by other people who are going through the same thing to talk and provide support	15 (16.7)	44 (48.9)	15 (16.7)	14 (15.6)	2 (2.2)
Being in familiar surroundings	8 (8.9)	32 (35.6)	40 (44.4)	10 (11.1)	0
Being at my home	8 (8.9)	30 (33.3)	39 (43.3)	13 (14.4)	0
Being in a calm and peaceful atmosphere	0	26 (28.9)	64 (71.1)	0	0
Free of pain and other symptoms (e.g. breathlessness/nausea)	0	16 (17.8)	74 (82.2)	0	0
Having support with my psychological wellbeing (feelings of worry, anxiety or depression)	1 (1.1)	28 (31.1)	61 (67.8)	0	0
Being able to maintain my dignity and self respect	1 (1.1)	18 (20.0)	71 (78.9)	0	0
Feeling safe	0	18 (20.0)	71 (78.9)	0	1 (1.1)
Being involved in decisions about my care	0	15 (16.7)	72 (80.0)	2 (2.2)	1 (1.1)
If I were not able to decide, then being able to involve my family or people I trust in decisions about my care	2 (2.2)	27 (30.0)	60 (66.7)	1 (1.1)	0
Having support with practical and/or financial issues	6 (6.7)	35 (38.9)	43 (47.8)	4 (4.4)	2 (2.2)
Not dying alone	14 (15.6)	18 (20.0)	47 (52.2)	9 (10.0)	2 (2.2)
Not feeling judged due to my ethnicity	17 (18.9)	24 (26.7)	45 (50.0)	2 (2.2)	2 (2.2)

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Terrence Higgins Trust 439 Caledonian Road, London N7 9BG
Tel: 020 7812 1600 **Email:** info@tht.org.uk **Website:** tht.org.uk **THT Direct:** 0808 802 1221