Waverley care

“Why am I still angry?”

EXPLORING THE FOURTH 90 IN SCOTLAND

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To cite this report: Akuffo, E., Bashorun, T., O’Connor, A., Goff, J., Kay, K., Marques Ferreira, V. M., McCormick, C., and Summer, S. (2023). ‘Why I’m Still Angry’: Exploring the fourth 90 in Scotland. Waverley Care

Acknowledgements

We would like to express our gratitude to everyone that has contributed to this research project.

First and foremost, we would like to thank all of the participants who took part in our research for taking the time to complete the survey, for sharing their experiences, and for their willingness to contribute to the advancement of knowledge in this field. We understand that taking part in research can be time-consuming and sometimes demanding, and we appreciate their efforts and dedication to this project. Their contributions will help us to improve our understanding of the topic and make a difference in the lives of people living with HIV in Scotland. We would like to assure all participants that their privacy and confidentiality have been protected throughout the study, and that their participation is greatly appreciated.

Thank you to the Alliance Scotland, whose funding provided the support needed to carry out our research.

We are also grateful to each of our colleagues in Waverley Care who helped us to recruit participants and to promote the research. Without their help, this research would not have been possible.

Overall, this research was made successful through the collaboration and support of each contributor. We are deeply grateful for their help and commitment.

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1. INTRODUCTION

1.1 About this Research

Waverley Care is a Scottish Charity that takes a positive approach to HIV, Hepatitis C and Sexual Health. We work closely with communities, starting conversations about these issues, encouraging people to access testing and empowering them to make choices that improve their health and wellbeing.

Our vision is for a Scotland where no-one faces HIV alone. Where it is simple to find out your status and access the support you need. Where stigma no longer exists, and open conversations about HIV, hepatitis C and sexual health are the norm. We will achieve this through our prevention, support and influencing work. Nonetheless, a crucial step in this journey is identifying and challenging the marginalisation HIV positive communities continue to face in Scotland today.

Waverley Care was funded by Alliance Scotland to carry out research exploring what it means to live well with HIV in Scotland today. This report describes the research findings gathered through a national survey carried out in February – August 2022

The research was mixed methods and designed using a person-centered-informed participatory action research approach.

1.2 Context

About the Fourth 90

In this section, we provide a brief secondary analysis delving into the context surrounding the experiences of people living with HIV (PLWH) in Scotland today. The goal of which is to gain a deeper understanding of the complexities and challenges facing PLWH in Scotland today, thus informing efforts to improve their quality of life.

To date, UNAIDS (the Joint United Nations Programme on HIV/AIDS) 90-90-90 targets have led to significant advancements in the clinical care and treatment of PLWH. The '90-90-90' targets are a set of global targets for the HIV response, set by UNAIDS in 2014. The targets aimed to achieve the following by 2020:

- 90% of all people living with HIV will know their HIV status
- 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy
- 90% of all people receiving ART will have viral suppression

Following the Covid-19 pandemic, UNAIDS (2022) has now updated its targets to 95-95-95 by 2025:

- 95% of all people living with HIV will know their HIV status
- 95% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy
- 95% of all people receiving ART will have viral suppression

Both internationally and within Scotland, a significant number of PLWH have been diagnosed and have access to antiretroviral treatment. Nevertheless, the community still faces various forms of marginalisation, preventing PLWH from experiencing a good quality of life (The Lancet HIV, 2019). In response, and in tandem with the progression of UNAIDS targets, discourse surrounding the need for a ‘fourth 90’ has emerged in the HIV sector (Lazarus et al., 2016; British Journal of Nursing, 2018). The ‘fourth 90’ refers to a goal that 90% percent of PLWH with viral suppression should have a good quality of life. While the fourth 90 is not formally included in the UNAIDS goals, it is increasingly understood as essential in addressing the lived impact of marginalisation on PLWH.

The Role of Marginalisation

Marginalisation refers to the act of excluding and stigmatising certain groups or individuals in society. This process can take various forms and can greatly affect access to resources, opportunities, and power. It can occur at the individual, community, and societal levels and can be based on factors such as HIV status. However, the marginalisation of PLWH is often compounded by other aspects of their identity such as race, ethnicity, gender, sexual orientation, age, or socioeconomic status. Accordingly, this experience of marginalisation can have a detrimental impact on the overall quality of life of PLWH.

Marginalisation is a Barrier to the Fourth 90

The impact of marginalisation on the quality of life of PLWH is broad and well evidenced (Hibbert et al., 2018; Holzemer et al., 2017; Onyebuchi-Iwudibia and Brown, 2014; Miller et al., 2016; Turan et al., 2016; ViiV, 2020). Studies have shown that PLWH are more likely to experience poor mental health when compared to the general population (Remien et al., 2019; Orza et al., 2015; Flowers et al., 2013; Rhodes et al., 2018; Rezaei et al., 2019). This can be attributed to the ongoing stigma and discrimination that PLWH face, which can lead to feelings of isolation and a lack of social support. Furthermore, PLHIV may face barriers to accessing healthcare and adhering to treatment, which can have a negative impact on their physical health (Glendinning et al., 2019; Bolseqicz et al., 2015; Sung-Hee et al., 2015; Poppa et al., 2004).

Research has shown that PLHIV are more likely to live in poverty, be unemployed, and have lower educational attainment (Jones et al., 2021; Solomon et al., 2021). These factors can contribute to a lack of access to basic needs such as food, housing, and social connection, which can further reinforce the marginalisation that PLHIV experience.

Societal marginalisation of PLHIV also occurs through social representations of HIV and its transmission. While public health campaigns take a stigma-challenging approach to HIV, a meta-analysis by Nerlich (2022) found stigmatising framings of HIV remain prevalent in UK media. This undermines action taken by the HIV sector to challenge stigma in the general public, while PLWH subsequently experience further marginalisation as a result.

Intersecting Marginalised Identities

Where the identity of PLWH intersects with other marginalised identities, PLWH experience a disproportional impact on their quality of life. For example, men who have sex with men experience high rates of problem alcohol use, poor mental health, and abuse, in addition to lower rates of resilience to stressful life events (Strongylou and Frankis, 2020). People from African communities are more likely to be affected by restrictive immigration policies and less likely to be represented in decision making processes that affect the services they access (Nakasone et al., 2020). People who inject substances affected by Glasgow’s HIV outbreak are more likely to be houseless or in temporary accommodation (64%) when compared to a rate of 25% among the general population (National HIV People who Inject Substances Oversight Sub-Group 2021). It is therefore clear that identities interact with HIV and reinforce each other to result in a unique lived experience of marginalisation.

"My challenges are very human, but they are often exacerbated because I'm living at the cross-roads of three marginalised identities, being a black woman living with HIV."

(Kasadha, 2018)

The persistent effects of marginalisation impede PLWH from achieving a good quality of life and limit their participation in the design of services, policy and societal perspectives intended for them. Thus, it is important to identify and address the factors that contribute to marginalisation of PLWH in Scotland in order to mitigate its effects on quality of life. In light of this, our research explores what aspects constitute a 'fourth 90' target in a Scottish context, with the purpose of finding a roadmap toward 90% of PLWH having a good quality of life

Meanings of Self-Care (Claisse, Kasadha and Durrant, 2021)

I wait, notes in hand
my turn to speak
share my experiences
We find options between words and screens

Moving and swaying

One pill or more to manage

And we go again, living

Fresh air, I breathe deeply
taking it all in
finding comfort with new faces
finding safety with old friends and kin

Moving and swaying

One pill or more to manage

And we go again, living

I get stuck in thoughts
feel small when I'm not heard

Moving is weighted

Living feels scarred

Moving and swaying

One pill or more to manage

And we go again, living

Today is a good day to take care of me
surviving to thriving

Hold my own, daring to ask

So I go on living

2. METHODOLOGY

The following research section outlines the methodology employed to explore the experiences of PLWH in Scotland today.

The research for this project was designed using a participatory action research (PAR) approach and was informed by a person-centred attitudinal framework. The research used a mixed methods approach, including both quantitative and qualitative data collection via a survey.

2.1 Participatory Action Research

PAR is an approach used in social research where communities usually the subject of research are empowered to take ownership over research carried out with the communities from which they are a member (Walter, 2009). Through PAR, traditionally researched communities are actively involved within all stages of research design (Chataway, 1997), valuing their experiential knowledge by providing a means to influence the development of policy, practice and societal perspectives that affect them (Baum, 2006).

The research described in this report uses a PAR approach as described by Baum (2006). Five Co-Researchers were employed by Waverley Care. The Co-Researchers participated in an action-based cycle of learning about research, reflecting on the process of research, exploring what the research meant in the context of their community identities, and determining what actions should follow. The process was supported by two research staff at Waverley Care, whose role was to provide resources and information determined as required by the Co-Researchers.

In contrast to traditional linear processes in social research, PAR is an inclusive cyclical process where each step of reflective action informs the next (Wadsworth, 1998). This was mirrored in the process of designing the research described in this report, where the Co-Researchers and Researchers worked in partnership to shape the research scope, define the data collection strategies, analyse findings and define the consequential actions (Baum, 2006). An awareness of power dynamics was maintained throughout the process, with the Researchers implementing strategies to prevent the emergence of oppressive power dynamics often experienced by traditionally researched communities. Such strategies were informed by a person-centred attitudinal framework and are summarised in the following section.

2.2 Person-Centred Attitudinal Framework

The design of research described in this report was informed by a person-centred attitudinal framework (Proctor & Napier, 2004). The person-centred approach is a humanistic and relational psychotherapeutic model that involves an acute awareness of and sensitivity to power dynamics (Sanders, 2004). While the approach emerged as a clinical practice, the attitudes held within the person-centred approach facilitate the effective development of PAR by offering a framework of informative attitudes, namely empathy and unconditional positive regard (Rogers,1957). When implemented as part of researcher practice, these attitudes can safeguard the power of traditionally researched communities when participating in the process of PAR design with Researchers.

In the context of this research, the person-centred attitudinal framework informed the PAR approach by facilitating the Researchers to implement power-aware safeguarding methods through reflective practice and integrated evaluation.

2.3 Reflective Practice

Reflective practice in research refers to the process of critically examining and evaluating the practices and processes of Researchers in order to improve the quality and integrity of the research. It involves reflecting on the researcher's own biases, assumptions, and perspectives, and how they may influence the research design, data collection, and analysis. Thus, we employed reflective practice within the design and conduction of this research for these purposes.

The Researchers participated in a process of reflective practice in tandem with the wider research process. This involved the Researchers participating in debriefs following each engagement session with the Co-Researchers. The Researchers explored their experience of the process during debriefs, as well as planning the implementation of any actions directed by the Co-Researchers.

The aim of reflective practice was to support the Researchers in offering empathy and unconditional positive regard to the Co-Researchers, thus preventing the displacement of power by maintaining a consistent awareness of its presence (Rogers, 1957). By offering empathy as understood through the person-centred lens the Researchers were able to listen to the experiences of the Co-Researchers by stepping into their world while maintaining the 'as if' quality (Rogers, 1951). In other words, by actively listening to the experiences of the Co-Researchers while refraining from taking power through interpreting their experience through the Researchers internal frames of reference (Proctor & Napier, 2004). In this way, the Researchers were equipped to more effectively act on the directions of the Co-Researcher.

Similarly, by offering unconditional positive regard, the Researchers prioritised a valuing of the phenomenological experience of the Co-Researchers, meeting them with warmth, but without possessiveness that may risk the displacement of power (Rogers, 1957). Through offering empathy and unconditional positive regard while maintaining an awareness of power, a relational environment of openness and collaboration was created between the Co-Researchers and Researchers, thus providing a safe space to experience the PAR approach while improving the subsequent quality of data gathered.

2.4 Integrated Evaluation

As part of effective PAR, opportunities for the Co-Researchers to evaluate the resources, approach and outputs were integrated throughout the process. This included both immediate opportunities to offer feedback during engagement sessions, subsequently actioned prior to the next contact point, as well as ongoing anonymous opportunities to offer feedback through a digital feedback box. The digital feedback box was hosted on a private website built by the Researchers to host information generated by the Co-Researchers throughout the process.

Providing consistent opportunities for the Co-Researchers to offer feedback on any part of their experience, as well as actioning the feedback in a transparent manner, benefited the research in two ways. Firstly, the Researchers ensured the Co-Researchers were able to influence the process unaffected by the power dynamics experienced when feedback is personally identifiable. Secondly, by taking action on feedback provided by the Co-Researchers, a relationship of trust and collaboration was developed between the Researchers and Co-Researchers. Together these factors informed the effective use of PAR, as well as the subsequent data described in this report.

2.5 Survey

An online survey (appendix 2) was carried out to explore what it means to live well today in Scotland in view of the fourth 90. An online survey was chosen as the methodology for this research study for several reasons.

Firstly, online surveys allow for greater flexibility in terms of question format and response options (Fielding, Lee and Blank, 2016). By collecting data in this way, the design was able to include a variety of question types, such as multiple choice, open-ended, and rating scales, to gather data in a way that was tailored to our specific research question.

Secondly, online surveys can reduce the bias associated with certain types of sampling methods. For example, self-selection bias is less of a concern in online surveys, as participants can choose to participate in the survey at their own convenience.

Thirdly, online surveys offer anonymity that can support reaching hard-to-reach populations that may be difficult to access through other methods, such as geographically dispersed or socially marginalised groups. These factors were relevant to consider in our research design because we were conducting research with PLWH living across Scotland.

In summary, the final survey design included a combination of qualitative and quantitative questions generated by the Co-Researchers. The survey data was collected from a sample of PLWH in Scotland and sought to measure various aspects of their quality of life.

The survey was carried out via SurveyMonkey between January and July 2022. It was promoted via social media and Waverley Care's services to engage a wider response. It gathered 55 responses in total and an 80% completion rate.

3. FINDINGS

3.1 What it means to live with HIV today

Before this report can make recommendations as to what is needed to help PLHIV live well with HIV today, it is necessary to provide a picture of what it means to live with HIV today.

The following is a picture of a person experiences their personal, professional, social and sexual life while living with HIV. The picture is a composite of the most common answers given in the survey and does not reflect any one individual's responses but serves to create a sense of what it is like to live with HIV in Scotland today.

- A person living with HIV today is unlikely to disclose their status in their everyday life. They feel the condition affects their employment, their ability to travel, and their benefits.
- If the person is employed, they are more likely to withhold disclosing their HIV status to their employer, even if they feel like they do not have a choice in doing so and worry that they would be discriminated against in the workplace if they did disclose.
- If they are on benefits, they feel obliged to disclose their status, even if they have the choice not to.
- Outside of work, the person is likely to have changed their social life since their diagnosis, due to their changed mental health or from others judging them.

Although they may have cut off personal relationships for these reasons, they have also gained new relationships and formed new community since their diagnosis.

- The person may or may not have sexual relationships, with their decision based on their HIV status, their changed libido or how attractive they feel as a result of their HIV status. If they have an undetectable viral load, they are more likely to have unprotected than protected sex.
- They are more likely to look after their physical health and wellbeing but suffer from a lack of support to maintain this or deal with the physical effects of the condition, and are likely to have poor diet and nutrition and bad sleeping patterns.
- They are likely to have poor mental health and wellbeing, with a tendency towards anxiety, depression and low self-esteem, and at times suicidal thoughts. They do not like attending mainstream support services because of the potential for stigma or judgement, so would like to attend group support sessions specifically for PLHIV. Although they do have a positive outlook on life.
- They do not feel living with HIV is like any other long-term medical condition, largely due to the mental health impact and experience of stigma in society.
- They feel they have to educate others about their condition and tend only to disclose their status to close family and friends, or in spaces they perceive to be “safe”.
- They do not view general health and social care services to be safe, and often experience discrimination when trying to access common services such as hair removal or dentistry.
- They may have had support in these areas, but since the Covid-19 pandemic services around physical and mental health and wellbeing stopped and have not re-started.
- This person living with HIV can be any age.
- But in particular, a person who is ageing tends to feel isolated, live with poor mental health and worry about a lack of community and support as they are the first generation to live to old age with HIV.

3.2. Financial and work life

We asked respondents a series of questions to better understand how their HIV status affects their **financial and work life.**

3.2.1 Key findings:

- Respondents felt that living with HIV most affected their employment, benefits and travel.
- When respondents felt like they had a choice of whether to disclose their HIV status:
    - an almost equal number chose to disclose (51%) as chose not to disclose (49%) their status to their most recent employer.
    - Considerably more chose to disclose (69%) than chose not to disclose (31%) their HIV status to their work-related or ill-health benefits advisor.
- When respondents felt like they did not have a choice of whether to disclose their HIV status:

    - More chose not to disclose (83%) than chose to disclose (17%) their status to their most recent employer
    - Considerably more chose to disclose (77%) than chose not to disclose (23%) their status to their most recent employer
- Of the respondents who had disclosed their HIV status before, more had experienced discrimination in the workplace than at an educational institution or by their benefits advisor.
- A quarter of respondents felt they would definitely be discriminated against by their employer if they disclosed their HIV status.
- In the job application process, most respondents would disclose their HIV status after a few weeks or months in the role (25%) or in the application form itself (25%), rather than at an interview (5%) or on their first day (10%).

3.2.2 Detailed findings:

We asked respondents a series of questions about their financial and work life to better understand how their HIV-positive status affects this area of their lives. As with all experiences of financial and work life the survey results were mixed, but some clear issues emerged.

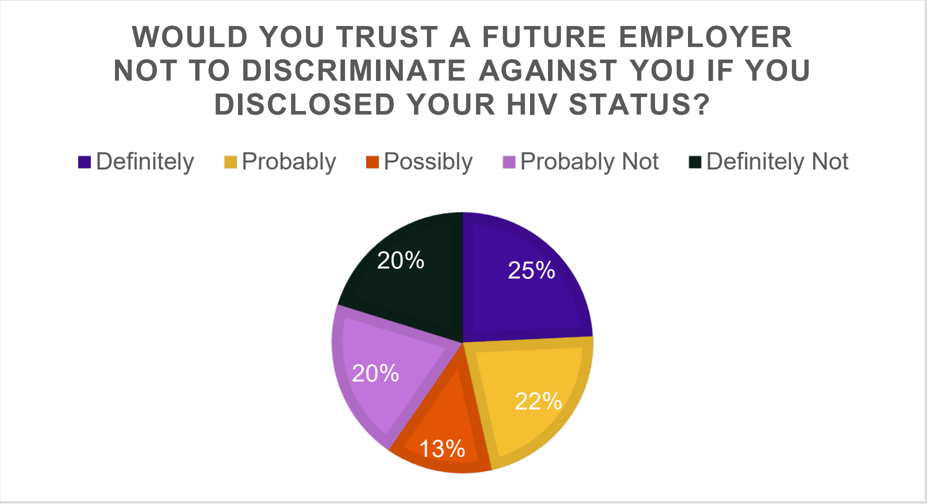
When asked whether living with HIV affects a list of areas of financial or work life, most respondents felt that it affected their employment (48% of all respondents), benefits (39%), and travel (33%). Respondents considered their HIV status to least affect their housing (20%) and education (11%). Interestingly, 28% of respondents stated that their HIV had affected none of the listed aspects of their financial or working life.

A significant majority of respondents (86%) said they were able to choose whether or not to disclose their HIV status to their most recent employer, with an equal number choosing to disclose or not – 44% choosing to disclose and 42% choosing to withhold. Of the respondents who felt they did not have a choice in disclosing their status, 11% had not disclosed even though they were legally required to do so, and 2% had disclosed their status only because they were legally required to do so.

Significantly, 64% of all respondents reported claiming some work-related or ill-health benefits. This compares to 15% claiming out of work benefits and in Scotland overall (Scotpho.org.uk, 2022).

Fewer of the respondents claiming benefits felt they were able to choose whether to disclose their HIV status to their benefits advisor (also known as the DWP): of respondents receiving benefits, 38% disclosed their HIV status to their benefits advisor by choice; 17% did not disclose their status by choice; and 10% did not disclose their status because they did not feel comfortable doing so. 35% of respondents disclosed their status but did not feel they had a choice.

75% of respondents stated that they had disclosed their HIV status in the workplace, at an educational institution or from a benefits advisor. When asked if they were to disclose their HIV status to an employer in the future, responses were relatively evenly balanced as to whether they would trust their employer not to discriminate against them in the workplace. However, it is important to note that 40% of respondents answered either “probably not” (20%) or “definitely not” (20%)



Similarly, responses were relatively evenly weighted when respondents were asked if they felt their HIV status affects their professional opportunities (i.e., chances of finding work, progressing in a current role, or developing skills): 38% responded “definitely” (31%) or “probably” (7%), and 40% responded “probably not” (18%) or “definitely not” (22%), with the remaining 22% responding “possibly”.

More than half of respondents (52%) stated they would never disclose their HIV status during the job application process. Of the respondents who stated they would disclose their status, 25% stated they would disclose their status at any stage of the job application process and 25% stated they would disclose after a few weeks or months in a new role. 20% would disclose their status in an application form, 15% when they were offered the job, 10% on their first day, and 5% at an interview.

3.3. Social and Sex Life

We asked respondents a series of questions to better understand how their HIV status affects their **social and sex life**.

3.3.1 Key findings:

- 60% of respondents felt that their social life had changed since their HIV diagnosis.
- Around half of respondents felt that their social life had been affected due to being judged or stigmatised because of their HIV (54%) or the mental health impact of living with the condition (50%).
- Respondents noted the negative impact on their social life of having to either disclose their HIV status or not.
- Although nearly half of respondents who felt their life had changed since their HIV diagnosis had lost or cut off personal relationships, a similar number felt they had gained new personal relationships.
- It is notable that some respondent mentioned the long time periods they had been living with HIV – over 25 years – and so the changing impact on their social lives over this time.

- A large minority of respondents (43%) stated that their HIV status affects whether they are sexually active, and over half (54%) felt that living with HIV affects how physically attractive they feel.
- Those respondents who have undetectable viral loads are considerably more likely to have unprotected (71%) than protected (11%) sex.

3.3.2 Detailed findings:

Social life

Most respondents stated that their social life had changed since their HIV status (60% stating it had changed; 23% stating it had not changed; 17% stating they were not sure).

When given a list of social issues related to their HIV-positive status, respondents felt that their social life was mostly affected by them being judged or stigmatised (54%) or from the mental health impact of living with HIV (50%), and least affected by the financial impact of living with HIV (13%).

Some of the respondents elaborated on this question in the comment section, with two respondents noting the connection between disclosing their status and their social life:

> *'Generally my social life is unaffected, however, as I have not disclosed my status to many people or friends, I sometimes fear I keep people at a distance so that I do not have to share more personal details about myself.'*
>
> *'Fear of having to disclose my status and subsequent rejection'.*

Of those respondents who said their social life had changed since their HIV diagnosis, 50% stated they had lost personal relationships, 44% stated they had cut off personal relationships and 39% stated they feel isolated from a community they used to be a part of. However, 44% of respondents also said that they had gained new personal relationships and 22% said they felt part of a new community. When given the chance to comment, some respondents noted the long time period they had been living with HIV (25 and 30 years respectively) and so their social lives had naturally changed. Others mentioned a general sense of distance from their social life:

> *'I have become less confident and more isolated as a result'.*
>
> *'I feel much more isolated and lonely'.*
>
> *'I am less likely to develop close friends. Less spontaneous for nights out due to planning meds and rest'.*

Sex life

Just over half of respondents (51%) considered themselves to be sexually active. A large minority of respondents stated that their HIV status affects whether they are sexually active (43%) and affects their libido (44%), and over half (54%) stated that living with HIV affects how physically attractive they feel.

Encouragingly, no respondents engaged in unsafe sex, that is, no-one stated they have unprotected sex and have detectable viral loads. Most respondents (64%) stated that the type of sex they have is because of their HIV status: most respondents either sometimes (27%) or always (22%) have unprotected sex and are undetectable, or do not have sex

(27%). Fewer respondents noted having protected sex while being detectable (4%) or undetectable (11%). Some respondents noted the connection between the type of sex they had and their HIV status:

> *'I actually felt like I took more risks after I tested positive (after I was undetectable of course)... I think this was linked to a brief period of hopelessness I felt after testing positive. Like it didn't matter anymore'.*
>
> *'I used to have sex always protected but I choose to abstain now … [to] save me from heartache after disclosing my status'.*

3.4 Physical Health and Wellbeing

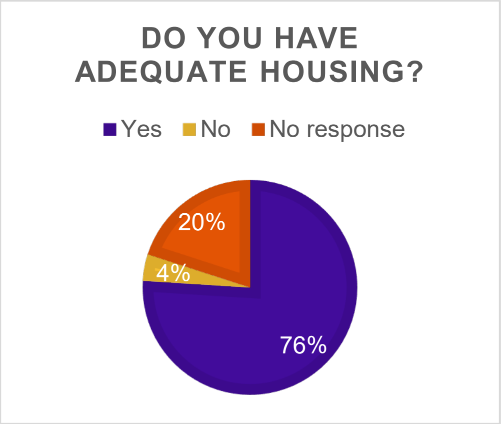
We asked respondents a series of questions to better understand how their HIV status affects their **Physical Health and Wellbeing.**

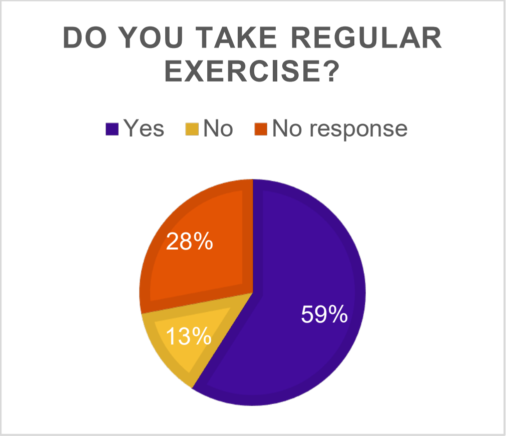
3.4.1 Key findings:

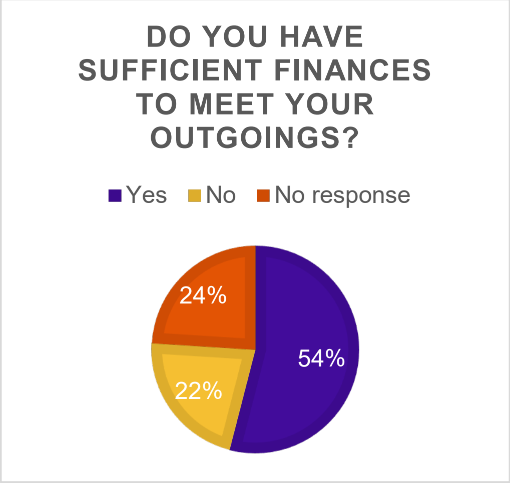
- Respondents tended to have positive physical health and wellbeing, except for regular sleeping patterns.
- Significant minorities feel they do not have a good diet and nutrition (22%) or have sufficient finances to meet outgoings (22%).
- Respondents commented on how living with HIV made them focus more on their physical health and wellbeing and noted the positive impact support services had played in their improved physical health and wellbeing.
- Respondents suggested their physical health and wellbeing could be improved by having more coordinated medical support within the NHS and more government-level support, in particular around the effects of an increasingly ageing community of people living with HIV.
- Respondents also wanted more support to maintain their physical health and wellbeing related to their HIV status, such as gym initiatives and massage, as well as specified support services such as peer and group support.

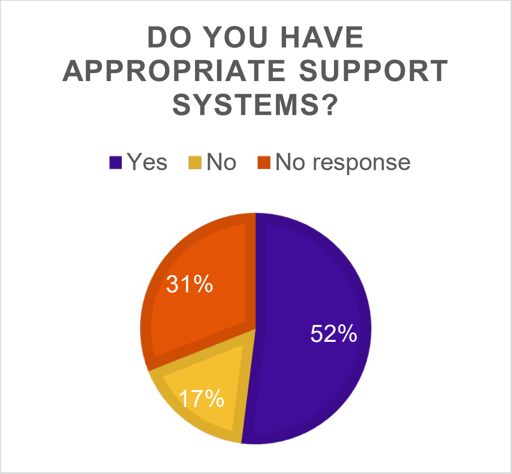
3.4.2 Detailed findings:

Encouragingly, respondents tended to have positive physical health and wellbeing, as the following charts illustrate:









It is significant to note that although most respondents replied in the positive to these questions, there were significant minorities who feel they do not have a good diet and nutrition (22%) or have sufficient finances to meet outgoings (22%). Poor diet and nutrition can have a strong negative affect on overall physical and mental health, and research shows that financial instability can lead to poor mental health.

The only aspect of physical health and wellbeing that most respondents replied negatively to was in having regular sleeping patterns with 61% of respondents answering no to ‘do you have regular sleeping patterns’.

Regarding these categories, some respondents commented that their physical health and wellbeing had improved or become more of a focus in relation to their living with HIV:

> *‘I was living healthily and exercising regularly before testing positive, and that has continued after. If anything, being a generally healthy person has become more important to me’.*
>
> *‘I would have answered a lot of this differently in the past. However, I've been living with HIV for a long time now and am in a good place with everything these days’.*

Others noted the significant impact of support services on their physical health and wellbeing:

> *‘If it was not for Positive Help and Waverley Care [I] sincerely believe that there would be a good chance that I would no longer be alive’.*

Others connected mental health and wellbeing to their physical health:

> *‘I feel isolated both physically and emotionally’.*
>
> *‘Stress and anxiety and general mental health issues cause me concern’.*

Respondents were asked if there were any physical health and wellbeing services or types of support that they wished were available to people living with HIV. Respondents’ comments fell under the following categories:

- ***Medical support**.* Respondents noted the need for coordinated medical support both between NHS boards in Scotland and, more specifically, for coordinated provision covering all areas of healthcare for a person living with HIV. One respondent noted that stigma and discrimination around HIV was still making mainstream health and wellbeing services inaccessible.

- ***Government support**.* Respondents commented on the need for increased support at government level to improve their physical health and wellbeing, in particular the need for recognition at government level of an increasingly ageing community of people living with HIV. Respondents also noted that their physical health and wellbeing could be improved with more government support rather than having to rely on the third sector; others mentioned the need for more help finding work.

- ***Advice & information**.* Respondents noted that their physical health and wellbeing could be improved by receiving better advice and information around pregnancy while living with HIV, living with co-morbid conditions, and receiving accessible benefits advice.

- ***Activities & services**.* Many respondents mentioned different types of activities and services they felt would improve or maintain their physical health and wellbeing, such as massage, due to soreness associated with long-term medication use, or dietitians and other physical therapies. Multiple respondents mentioned their desire for more gym initiatives targeted at PLHIV, perhaps with funding attached. One respondent suggested that PLHIV should have long-term access to the Edinburgh Leisure CAP (community access program) card. Respondents again mentioned the lack of services and activities targeted towards ageing people, noting that they felt very alone as they aged over 60.

- ***Location**.* Multiple respondents noted gaps in service provision and support in rural areas compared to cities in Scotland, leading to negative physical health and wellbeing.

- ***Support type**.* Respondents also noted the need for specific types of support around physical health and wellbeing, such as the return of peer support opportunities; the need for support and services that are not specific towards gender or sexual orientation, as it can be difficult to find support as a straight person; as well as looking for support that are both in group session format as well as one-on-one.

3.5 Mental Health and Wellbeing

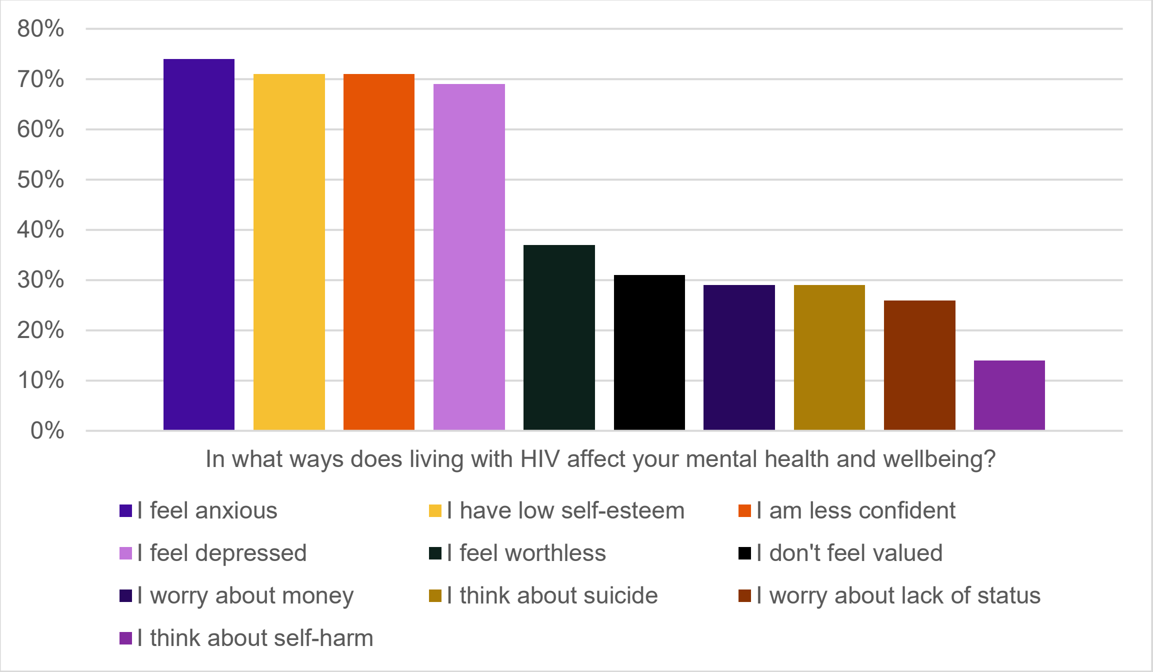
We asked respondents a series of questions to better understand how their HIV status affects their **Mental Health and Wellbeing.**

3.5.1 Key findings:

- Overall, respondents tended to be affected by poor mental health and wellbeing as a result of living with HIV, in particular experiencing anxiety, depression, low confidence and low self-esteem. Particularly notable is the high number of respondents (29%) who stated they think about suicide.
- Respondents wanted to access HIV-specific services, especially because the issues surrounding stigma related to HIV made them reluctant to access more mainstream services.
- Respondents want increased availability of group mental health resources and services, in addition to one-to-one services.
- They also expressed the desire for longer-term mental health support and for increased services in rural areas.

3.5.2 Detailed findings:

A large number of respondents felt that living with HIV affects their mental health and wellbeing, with 74% feeling anxious, 71% having low self-esteem, 71% feeling less confident, and 69% feeling depressed as a result of their HIV status. Although considerably fewer respondents stated they think about self-harm (14%) or suicide (29%), these figures are still high enough to be of significant concern and the responses together paint a picture of people living with HIV living with poor mental health and wellbeing.



Some respondents noted not being able to distinguish between their general mental health and wellbeing and that which is directly related to living with HIV:

> *'After 30+ years of living with HIV it's hard to attribute any mental well-being concerns to the diagnosis especially as I am in good health'.*

Others did not see a correlation between their mental health and living with HIV:

> *'Living affects mental health & wellbeing even before HIV'.*

> *‘I have accepted it and just get on with life, there are much more worrying things to deal with’.*

Others still noted the trauma associated with living with HIV and the impact this has had on their mental health and wellbeing:

> *‘My mental health definitely requires more care and attention these days than it did prior to my HIV diagnosis. I believe the medication can also contribute to underlying anxiety and, although generally I'm content these days, there's a fair bit of trauma associated with my HIV diagnosis that can still be triggered from time to time’.*

Overall, a mixed picture exists but one where the majority expressed living with HIV had some impact on their mental health and wellbeing.

Respondents were asked if there were any mental health and wellbeing services or types of support that they wished were available to people living with HIV. Respondents’ comments fell under the following categories:

- ***HIV-specific support.*** Respondents noted they would benefit from mental health support designed specifically for people living with HIV, such as residential respite opportunities or counsellors trained specifically in issue related to living with HIV.
- ***Stigma.*** Respondents also felt that dealing with the stigma that surrounds HIV would benefit their mental health, noting that if the wider issue of stigma among the general population was dealt with, respondents would feel more comfortable accessing mainstream services, which they do not do so currently.
- ***Re-instituting cutback services***. Some respondents commented on how the services they would like to access were ones that they had in the past, but that had been stopped due to cutbacks, such as access to mental health nurses or welfare advice and support.
- ***Group services.*** Many respondents noted their wish for group alongside one-to-one support, in particular for the over-60s.
- ***Services in rural areas.*** Of large concern was the need for more widespread access to services that covers rural areas of Scotland, in particular giving people in rural areas the opportunity to meet others living with HIV.
- ***Longer-term mental health support.*** Respondents noted that they found mental health support such as counselling to be very beneficial to them when they were first diagnosed, but that this support was very short term and that they would benefit for longer-term/ongoing mental health support that lasts beyond the initial period after diagnosis.

3.6 Stigma

We asked respondents a series of questions to better understand how their HIV status affects their **Stigma.**

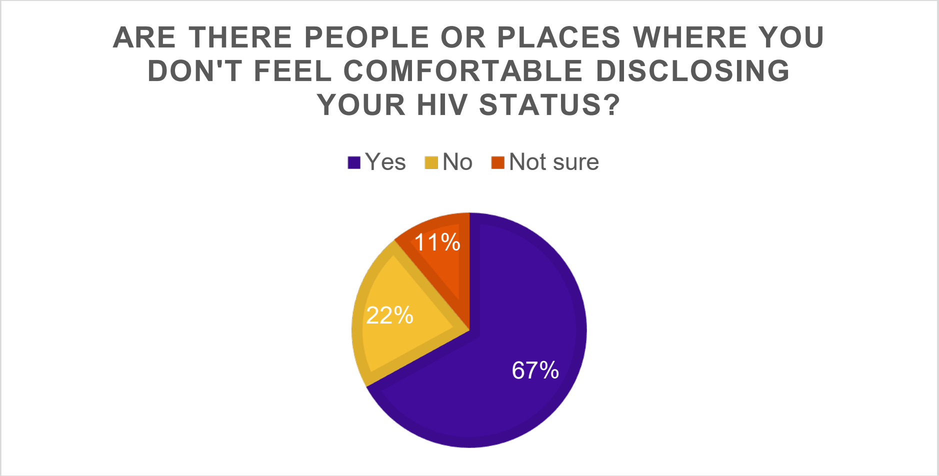
3.6.1 Key findings:

- Most respondents (67%) did not feel comfortable disclosing their HIV status in certain places or to certain people.

- Of those, most felt uncomfortable disclosing in casual social situations like work or hobbies, or did not disclose to anyone other than friends, family or in a perceived safe space like healthcare settings.
- Respondents felt that stigma affects their ability to live well because they need to educate others, they feel judged or judge themselves, or that stigma affects their relationships.
- A significant majority of respondents (72%) stated they have experienced self-stigma.
- Respondents generally did not feel that having HIV was like living with any other long-term health condition, stating that things like stigma and the negative mental health impact of diagnosis as aspects that made it unlike other long-term conditions.
- To reduce stigma, respondents felt there is a need for a new wider public health campaign to educate the general public about HIV, as well as a need for targeted education/training for benefits advisors in particular as their lack of knowledge and understanding around HIV has real-world impacts for those applying for support.
- Respondents noted a reduction in services and ability to find community since the onset of the Covid pandemic.
- Respondents overwhelmingly felt that peer support should be an important part of HIV support services.

3.6.2 Detailed findings:

A significant majority of respondents stated that there were people to whom or places where they do not feel comfortable disclosing their HIV status:



Respondents who answered yes were asked to elaborate mostly said they did not disclose their HIV status to anyone other than close friends and family or in a safe space, such as health services:

> *'Most places to be honest as you never know what the reaction will be and past experiences have made me wary unless I know I am in a safe space and am confident of a positive response'.*
>
> *'I only disclose to close and long term friends and occupational health se[r]vices'.*
>
> *'I have shared my status with less than a handful of friends. I'm not really at the stage where I'm very open about it. I have sometimes thought it would be nice to meet*

> *other HIV positive men, as that would be a safe space. I think this was initially offered to me when I tested positive but it never happened as it was around the same time covid took off'.*

Respondents also mostly stated that they did not disclose their HIV status in casual social situations, such as work or hobbies:

> *'In the company of strangers and certain social circumstances'.*

> *'Work and most other social interactions. I cannot see there is any value to disclosing my status; all I can see is a potential downside and "if they don't need to know, why tell them?" is my approach these days'.*

> *'Casual friendships. I have disclosed to my occupational health service but not other colleagues'.*

> *'Just anyone I come into contact with in my locality'.*

Some respondents stated that they did not disclose to anyone, or only when they had to; but some others stated that they were happy to disclose to anyone:

> *'Anywhere that I have to like the dentist, doctor, etc.'.*

> *'Lost that discomfort over the decades, their problem not mine'.*

When asked how HIV stigma affects their ability to live well now, more than half of respondents (56%) stated it was because they had to educate others about HIV. A significant number of respondents felt their ability to live well now was affected by them judging themselves because they have HIV (43%) or because they feel judged by others for having HIV (39%). A similarly high minority felt that stigma affects their relationships: by others having outdated perceptions of HIV (37%); it being more difficult to create relationships with others (37%); or by others being afraid of HIV (26%). Some respondents noted specific issues around stigma:

> *'I feel I have to work much harder to be accepted by rural […] communities'.*

> *'A lot of the side effects of older style drugs and historical stigma have left their mark.'*

Leading on from this topic, a significant majority of respondents (72%) said that they had experienced self-stigma, when a person takes the negative ideas, judgements and stereotypes about people living with HIV and applies them to themselves.

In the co-production of this survey, co-researchers living with HIV often mentioned that they were told, often by medical professionals, that living with HIV is like living with any other long-term health condition. The co-researchers felt that this was an interesting position to take and questioned whether it was useful in reducing stigma or whether it erased the realities of living with HIV. Survey respondents had mixed opinions about this statement but tended towards disagreeing with the statement: 58% of respondents either disagreeing, somewhat disagreeing or strongly disagreeing, and 37% either agreeing, somewhat agreeing, or strongly agreeing that HIV is like living with any other long-term health condition. The most respondents disagreed (27%) with the statement, however, with respondents commenting on how their lived experience of having HIV did not feel like other health conditions:

> *'HIV is not just about taking medication. There's other things that impact my life, mental health the stress of past experiences'.*

> *‘I feel this is not a positive approach at all. People with diabetes or other long term conditions do not experience judgement and discrimination because of their conditions’.*

> *‘In some ways, it is not like diabetes, say, but in others it is. For me, getting HIV was associated with other traumatic events and it is hard to me to just treat it as a medical condition because of that’.*

Respondents were asked whether there were any people or sites that they feel need more education or training about HIV, as a means to reduce stigma. Multiple respondents noted that there was a need to update education around HIV to the general population:

> *‘I think it's also high time for a wider public health campaign to update people's HIV knowledge’.*

However, most respondents stated the need for benefits advisors to receive additional training as their lack of knowledge and understanding had real-world implications on people living with HIV’s quality of life, for example in education, housing or around PIP:

> *‘I have had bad experience with benefits in the past when I was unwell. They didn't seem to understand my condition’.*

> *‘I feel that the DWP think if someone's cd4 and viral load are fine then everything else regarding HIV is ignored. For example the long term effects are often ignored, the mental health effects are often downplayed’.*

Respondents also noted settings such as podiatry, dentistry or hair removal needed more education to reduce stigma:

> *‘[…] all have asked me not to return or wait till the end regardless of appointment time because of my status in the last five years’.*

Others noted the need for healthcare professionals such as GPs, pharmacists and home care and residential staff to have more education, in particular because of an ageing HIV community:

> *‘I feel myself having to educate my GP’.*

Some also noted more education and training needed for people who work in financial services or travel, as well as at schools and young adults aged 18 to 25.

Finally, we asked respondents how important it was to them to get peer support as part of HIV support services, peer support being when people use their own experiences to help each other. Respondents overwhelmingly found it important, with 100% stating it was important in some way and no respondents stating it was unimportant. Of those who found it important, 67% stated it was “very important”, highlighting the significance of peer support in our respondents’ lives.

3.7 Anything else?

To conclude the survey, we asked respondents if there was anything else they wanted to tell us about living well with HIV.

Mostly, respondents talked about the negative impact HIV had on their mental health and their quality of life:

> *‘The feeling of it being my fault and the problems that this causes me’.*

> *‘It can be very depressing.’*
>
> *‘Even though going to a gym or swimming pool helps mentally for a while these are solitary pursuits. Most days TV, Radio, Laptop and who I talk to at the supermarket checkout are the only company I have here in busy Edinburgh’.*
>
> *‘It sucks! I have fear which has lead me to not having sexual partners or relationships because they are scared and I can’t even talk to my own family about it as they pretend it's not happening (blind eye)’.*

At the same time, some respondents noted the positive advances around HIV, how it is a part of life, and the need for a positive outlook:

> *‘Life was difficult before HIV, money, rent, relationships & accommodation & it is now just a part of my makeup, as I've lived too long with it & can't really remember life without it’.*
>
> *‘Nothing stops me living well with HIV at this time, my meds work well with no side effects and I have no need for the support services on offer from the third sector. It is not that big a deal to live with HIV these days and I am grateful for the medical advances that we have benefited from’.*
>
> *‘I receive amazing care from Ward 41 Edinburgh. Checkups are very easy and everyone is always very friendly’.*
>
> *‘Be sure to live with hope. Sunshine facing life’.*
>
> *‘Live happily’.*
>
> *‘Keep hope alive’.*

Others noted the need for more education to reduce stigma, especially around U=U:

> *‘People to be humane and to get a better understanding of the disease’.*
>
> *‘Undetected means zero transmission, more media, newspapers need to promote this concept’.*
>
> *‘Changing the outdated perceptions surrounding HIV and removing the stigma would indeed make living with HIV like any other long term medical condition , but stigma currently makes this impossible’.*

A few mentioned the impact of HIV as a long-term condition:

> *‘I’ll be 50 this year and am concerned about long term impact of 30+ years of medications’.*
>
> *‘Long-term side effects have made life more challenging for me. Having periods of enforced unemployment have caused practical and mental health issues. My confidence has been impacted and I don't really see that changing’.*

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