

The UK People Living with HIV Stigma Survey 2015

Irina Lut

Family Planning Association, London

Introduction

The landscape for people living with HIV (PLWH) in the UK has changed dramatically over the last 20 years with significant advances being made in treatment and prevention methods that enable PLWH to have improved life expectancy and opportunities to be involved in fulfilling relationships. However, there is still much to be done to significantly reduce stigma and discrimination and continue to improve the quality of life, health and overall well-being of PLWH. The 2016 Public Health England 'HIV in the UK' report states that 87% of PLWH in the UK were diagnosed [1]. Of people living with diagnosed HIV, 96% were on treatment and a further 94% of those were virally suppressed, giving them an undetectable viral load. An *undetectable viral load* refers to the very low amount of HIV in a diagnosed person's blood (usually under 50 copies/mL) [2]. This significantly decreases sexual transmission of the virus to a partner [3] and is the key to the long-term health of PLWH [4]. It is crucial for practitioners and advocates to support their HIV-positive service users to truly understand the value proposition held within achieving and maintaining this 'new HIV status'. The new age of 'undetectability' and better knowledge about HIV transmission in the general population is necessary to reduce the stigma experienced by PLWH. The widespread awareness and appreciation of what it means for someone living with HIV to be undetectable will significantly contribute to ongoing stigma reduction interventions in the UK and to support the improvements in quality of life for PLWH across multiple areas of their lives.

The People Living with HIV Stigma Survey 2015 captured the feelings and experiences of 1576 PLWH in the UK and brought insight on HIV-related stigma and discrimination in the UK over the previous 12 months. Participants who completed the survey were given the option to take part in further research and a community researcher conducted semi-structured in-depth interviews. All figures and quotes within this article are from this work. Analyses of this comprehensive data set show that stigma is still a significant strain on people's lives and can be an impediment to enabling people to live well with their diagnosed HIV. Of survey respondents, one in three (34%) had tried to address an issue of HIV-related stigma or discrimination in some form. The statistical data and personal stories have enabled the survey team to produce report cards for public health and

clinical commissioning groups (CCGs) to commission cost-effective, targeted interventions and to identify where further research is necessary, specifically targeting women and young people. In 2015, the Stigma Survey UK did not ask respondents whether they were virally suppressed but this question is now included in current and future surveys.

Demographic information of study participants

Three-quarters of participants (75%; $n=1182$) were men and 82% ($n=970$) identified as men who have sex with men (MSM); 23% ($n=359$) were women of whom 96% ($n=325$) identified as heterosexual; and 2% ($n=31$) identified as transgender or non-binary. There were comparatively more UK-born men and fewer women from black, Asian and other minority ethnic (BAME) communities among participants. Almost two-thirds of participants were born in the UK and of white ethnicity. Overall, 63% ($n=989$) identified as white British or Irish, while 71% ($n=269$) of women identified as BAME. Of the 583 (37%) people who identified as belonging to an ethnic minority group, 310 (53%) were born in an African country. Approximately half (54%, $n=799$) were aged 35–50 years (Figures 1–3).

Mental health and wellbeing

Advancements in the treatment of HIV mean that people living with the diagnosis, who are successfully treated, can have a normal life expectancy in comparison to their HIV-negative counterparts [5], and from our survey, almost two-thirds of respondents reported feeling positive about life (64%) and in control of their health (61%). Yet approximately half also reported feeling shame, guilt and low self-esteem. In interviews, participants were asked about what it meant to them to be virally suppressed:

Knowing that I was undetectable and that I couldn't pass it onto anyone else made my mental state be in a really good place, it meant that sex was no longer a mine field. I got empowered by telling people. (Asian MSM, 36, Brighton, diagnosed 2010)

It's very empowering knowing that you can't transmit the virus, even for me who is in a relationship with someone who is positive, I still find it very empowering. (Black African male, 63, London, diagnosed 2002)

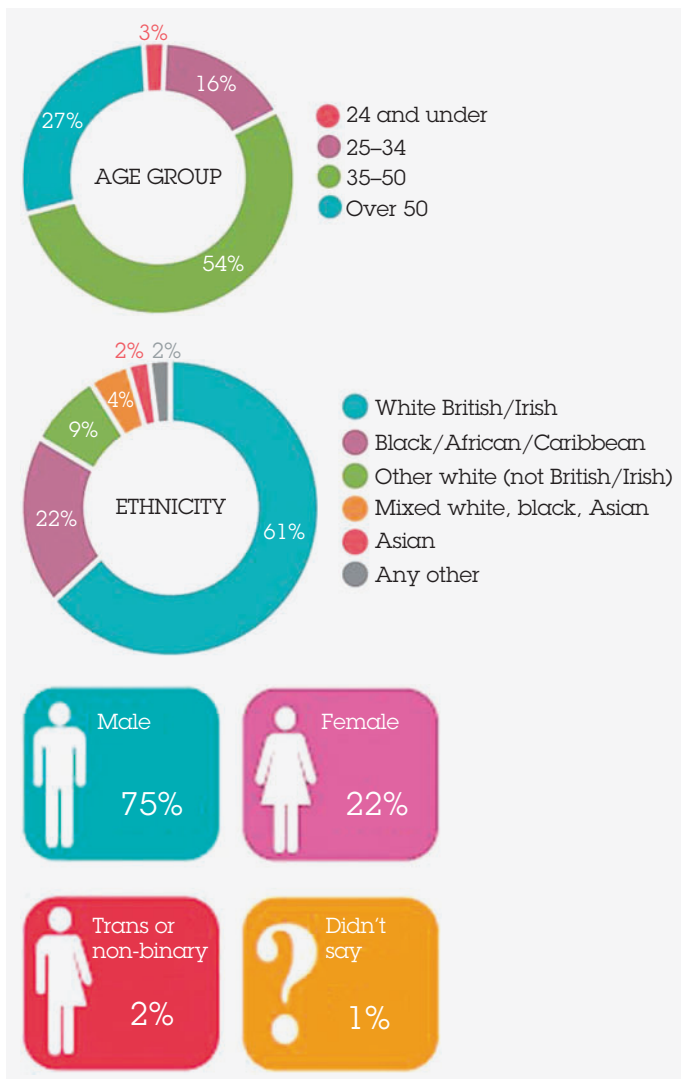


Figure 1: Demographic information on participants.

Being undetectable was considered to be empowering and valuable, helping to reduce internalised stigma felt by our participants and the psychological difficulties that can be associated with being HIV-positive:

Having been undetectable for so long now, that I'm not classed as being as infectious as I once was ... Being undetectable is a weight off my mind. Not completely, but it means that there is that little bit less of a risk. (White MSM, 35, southwest, diagnosed 2004)

Our 'new HIV status' has important implications for how people view themselves and consequently their

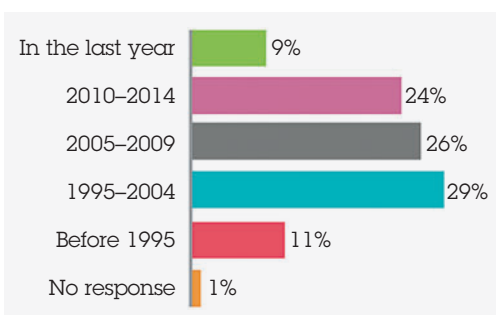


Figure 2: Participants' time since diagnosis in UK.

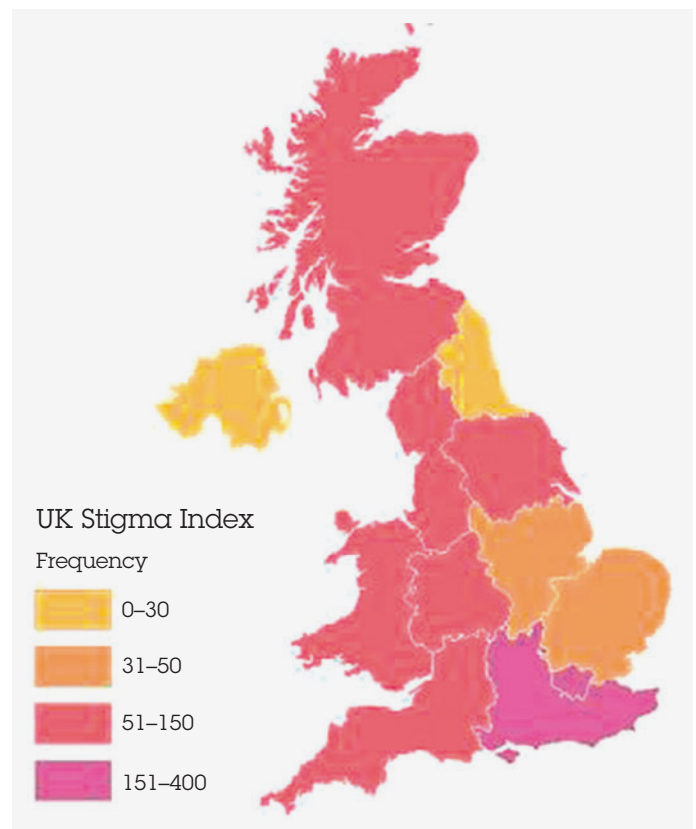


Figure 3: Regional distribution of all participants (n=1576).

ability to process their diagnosis and have meaningful, intimate relationships.

Personal relationships and the law

The survey asked participants about sharing their status with others as well as worries and experiences within personal relationships (Figure 4).

Nearly half (47%) reported being worried about sexual rejection within the last 12 months and 28% reporting having actually experienced this. Despite these findings, some interviewees described the confidence and power gained from knowing they are undetectable and therefore uninfected:

I think it's given people living with HIV more confidence, a lot more people are now saying, I'm not infectious, fine, then I'll go ahead and be a bit more confident in trying to find someone to date ... People who are HIV positive can now be a bit more relaxed about dating as

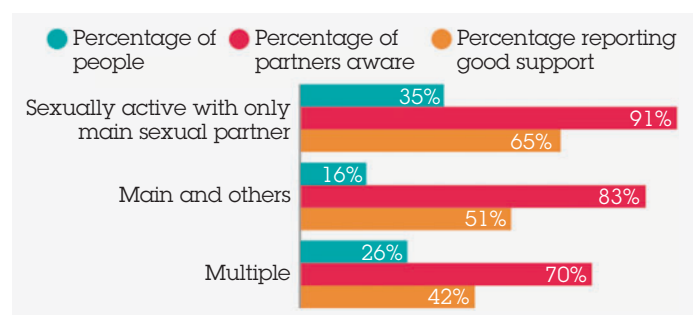


Figure 4: Awareness of HIV status and support in sexual relationships.

they know I'm no longer infectious. (Black African woman, 48, London, diagnosed 1996)

Being undetectable gives you power. (White MSM, 61, London, diagnosed 2012)

This positively impacted their self-assuredness with partners, giving people more freedom to have fulfilling relationships irrespective of their partner's serostatus:

I don't really think about it, I don't think about transmission. There are times when it pops into my head, but the risk isn't there, if it is it's tiny. Yes, it has made a difference, we can be spontaneous. (Black African woman, 24, London, born with HIV)

When asked about HIV and the law, 87% reported that both partners, regardless of HIV status, equally share responsibility for preventing transmission. However, one in five believed that transmission should be a criminal offence. This was nearly one-third for women and members of BAME communities but only 14% for MSM. The variability in opinions was unexpected but highlights the difference in experiences for women and men in relationships, and the impact of other factors such as family, culture or faith. The issue of criminalisation of HIV becomes inapplicable when someone is virally suppressed and the risk to their sexual partners is minimal. Nonetheless, overall two in five (40%) reported that the risk of criminal prosecution relating to HIV transmission has influenced decisions to tell others about their status in the past. People living with HIV deserve the ability to have sexual relationships without the fear of criminalisation. Better understanding of viral suppression within both the HIV-positive and HIV-negative population is vital to alleviating any anxieties around HIV transmission and thus addressing the feelings and experiences described here.

Support

Of all respondents in the Stigma Survey UK in 2015, nearly two-thirds (59%) had sought support in relation to their HIV status in the last 12 months. This was slightly higher for members of BAME communities (63%). Almost one-third (30%) received support from a local HIV-support organisation overall. This was slightly higher for women compared to others. Only 10% of BAME participants turned to online platforms for support compared to 20% of others. Whether in person or online, the diagnosed population in the UK is one of the prevention agenda's greatest assets. It has been shown that peer support is important in parallel to clinical care to enhance coping skills and improve psychosocial functioning in PLWH [6]. If peers inform one another about the significant benefits of achieving and maintaining undetectability, first-hand examples could act as motivators and inform people about the effectiveness of treatment as prevention. The willingness to support our peers was evidenced: half of participants reported they had provided

emotional support to other PLWH within the last 12 months. One in five had been involved in a programme or project providing assistance to people living with HIV. This proportion was even higher for women with over a quarter reporting supporting their peers:

Helping others with their diagnosis also helps me. (White British transgender woman, 58, London, diagnosed 1985)

I now work as a community representative in the HIV sector. I have been told that I have been an inspiration to others; this is extremely rewarding and empowering. (White British man, 58, London, diagnosed 1997)

Over time we expect that extensive awareness of 'undetectability' will serve to reduce stigma and discrimination, and improve adherence and increase testing.

Healthcare settings

There is good evidence that HIV-related stigma is associated with refusal of HIV testing, non-disclosure to partners, and lack of or reduced engagement with healthcare services [7]. In a study of 204 PLWH in the US, Rintamaki *et al.* found that people with high HIV-stigma concerns were 3.3 times more likely to be non-adherent to their medication regimens than those with low concerns [8]. Many PLWH or members of the general population do not know what it means to be virally suppressed and do not grasp the more personal benefits that span beyond clinical outcomes:

I've had women in tears, women who've been undetectable for years and no one has told them what it means to be undetectable. One woman said, oh my god all of that guilt can go and another one just broke down in tears. (White MSM, 54, London, diagnosed 1997)

Reaching this status can also serve as a motivational tool for people who may be experiencing difficulties with adhering to their treatment regimen:

For me it was something to strive towards, because I remember when I was taking my medication, I was waiting, waiting, to become undetectable. When you become undetectable, it's like, great I'm now normal. I'm as healthy as the next person. It was like, there is light at the end of the tunnel. (Asian MSM, 40, London, diagnosed 2005–2006)

The quote below, however, shows that some patients feel that their clinic teams may not be as in tune with the psychological and social benefits of achieving and maintaining undetectability:

I think, the medical community don't actually grasp the psychological implications of what it means to be undetectable, they just think, oh this is interesting research. They don't actually

think what it means to the patient. (White MSM, 54, London, diagnosed 1997)

Clinicians and nurses can create opportunities to acknowledge this and present more comprehensive information about not only the meaning, but also the impact of undetectability for personal relationships, when talking about adherence and viral load results. The information provided needs to be consistent, clear and repeated to enable risk management for all PLWH in the UK.

Education

Generally, HIV-negative people are still ill-informed on HIV and the modes of transmission [9]. One interviewee felt that despite being virally suppressed, he still describes people who look at him with fear:

So for me, I know that I take my medication, so I know that I'm not infectious. [But] for some people you can still see that fear in their eyes, they don't understand, even when you try to explain, to them you're just HIV positive, or you've got the AIDS virus. (White woman, 55, Wales, diagnosed 1994)

In our survey, participants were asked to rank what they felt were the most important actions that should be taken to address stigma and discrimination (Figure 5). The top three responses were: include HIV education in schools; raise public awareness and knowledge; and provide emotional, educational and referral support to PLWH. For transgender people, the third was also tied with advocating for the rights and provision of support to marginalised groups. For injecting drug users, the third was increasing evidence-based media coverage.

Within the HIV sector, some patients actively seek out treatment with the goal of reaching undetectability:

I asked to go onto medication because I knew that after a while it would mean that I would be undetectable. And that would make it even harder to pass it on, and that would make it even safer for my partner. (White MSM, 35, southwest, diagnosed 2004)

Comprehensive HIV education for all is the primary way to improve health outcomes and reduce the stigma experienced by PLWH. It has the potential to

open dialogue for support and empower PLWH to confidently challenge the stigma they feel from people in various settings of their lives.

Conclusion

The Stigma Survey UK 2015 data set provides insight into a range of issues from personal relationships to experiences in clinical settings for PLWH in the UK. Within clinical settings, HIV boasts of considerable patient involvement and a strong knowledge base within the community compared to other chronic conditions. In this new landscape of treatment as prevention and this critical time in the British-HIV response, care teams are a vital part of the puzzle in addressing stigma by supporting patients who are not as informed about undetectability and encouraging peer support around viral suppression. The data from both the Stigma Survey UK 2015 and US studies demonstrate that clinicians and nurses managing antiretroviral treatments are best placed to ensure that they adequately explain their patients' health status and particularly how undetectability can impact people's lives and relationships when their patients reach viral suppression. Stigma is one of the last obstacles to be tackled and a strong co-ordinated push towards a broad understanding of the benefits in achieving and maintaining an undetectable status is the next step in accomplishing the end of HIV-related stigma in the UK. Empowering people to live well with diagnosed HIV will support effective and appropriate disclosure, reduce stigma, and help change the national conversation around testing and the use of services. Redefining the language of HIV and promoting the widespread understanding of undetectability has the potential to significantly improve the lives of PLWH in the UK. Community members, service providers, stakeholders and policy makers all need to support the agenda of a 'new HIV status'.

The Stigma Survey team is currently running the Young People's Stigma Survey UK, open to 15–24-year-olds living with HIV in the UK (www.stigmaindexuk.org). We encourage all who are eligible to share their experiences with us so we can better understand stigma and discrimination in the lives of young people living with HIV in this country.

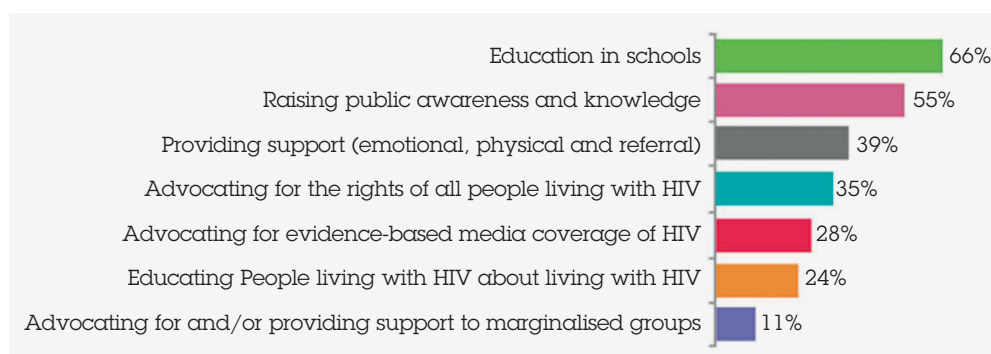


Figure 5: Addressing stigma and discrimination for PLWH.

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Correspondence: Irina Lut
 stigmasurvey@fpa.org.uk

Mental health and HIV: answers to the self-assessment quiz

1. The correct answer is **b**
2. Answers **a**, **b** and **e** are correct
3. Answers **b**, **c** and **e** are correct
4. Answers **b** and **d** are correct
5. The **sympathetic** nervous system causes release of the 'stress hormone' **adrenalin** from the **adrenal** glands as a result of perceived threat. This hormone causes an increase in the **heart** and **respiratory rate** as well as gastrointestinal effects such as **nausea/vomiting** and **diarrhoea**
6. Answer **d** is correct. EDMR stands for **Eye movement desensitisation and reprocessing**.
7. Any from the list contained in Box 6 in the article, including: reduced treatment adherence, loss of patient engagement, increased use of alcohol and drug use, clinical decline, increased hospital admissions, high-risk sexual behaviour and increased risk of onwards HIV transmission
8. Answers **b**, **c** and **d** are correct
9. Your answer could include: psychoactive substance use including alcohol, age-related or other neurological disease, e.g. Alzheimer's or Parkinson's diseases, CVD, hypoxia, drug side effects, cytomegalovirus infection, IRIS, hepatitis C, depression and others
10. Answers **b** and **d** are correct. Note that all PLWH should be screened for the presence of *both* mental health problems *and* cognitive difficulties within 3 months of their diagnosis