



Changing  
Perceptions

# Talking about HIV and attitudes

**Positive**✓**voices**  
the national survey of people living with HIV



## Acknowledgments

A special thanks to all the people living with HIV who took part in the Positive Voices survey, particularly those that volunteered their time and expertise to the Changing Perceptions project.

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Photos: Positive Voices participants and Positively UK peer mentors volunteered to be photographed for this report in order to give a face to HIV and help break down the stigma surrounding HIV.

Thanks to ViiV and Gilead for their support.

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Note on gender: when gender breakdowns are presented, transmen and transwomen were included in the gender groups with which they self-identified. Due to small numbers, those who identify as non-binary/in another way (representing 0.5% of Positive Voices respondents) are excluded from binary gender breakdowns.

# Introduction

In the UK, people living with HIV are from all backgrounds and walks of life. However, there are certain groups who are disproportionately affected – gay and bisexual men, migrants, people from black African and Caribbean ethnic communities, and people who inject drugs.

Today, HIV can be managed effectively with medication and regular check-ups. This means that people living with HIV, diagnosed and treated at an early stage, have a normal life expectancy. Being on effective treatment also means that people cannot pass the virus on to others.

Nevertheless, society's knowledge and attitudes have not kept pace with these developments. There are widespread misperceptions about HIV and negative attitudes, also known as stigma, can result in unfair treatment of people with HIV. There are many causes of stigma, such as inaccurate information about how HIV is transmitted and that the association of HIV with certain behaviours and lifestyles that some disapprove of. The intersection of HIV and other aspects of our lives - such as sexuality, gender and migrant status - can compound the negative attitudes that a person encounters and even how they feel about themselves. This report explores attitudes about HIV and experiences of how people think and feel about HIV.

This is one in a series of reports that brings a new focus to the diverse needs of people living with HIV today; blending personal stories with findings from Positive Voices – the largest, most representative survey of people with HIV to date. Through storytelling, people with HIV have brought the survey to life by putting statistics in the context of real lives in order to challenge attitudes and change perceptions about HIV.\* Each section gives recommendations for policy change to better meet the needs of people living with HIV.

These are our stories, we are sharing them with you because we believe that perceptions around HIV must change, so that we can lead healthy lives and be treated with dignity and respect.

Whether you are someone living with HIV, a researcher, politician, healthcare worker, commissioner, or simply stumbled across this report, we hope that these stories will resonate with you and change your perceptions of HIV.

\* Names are fictional and for descriptive purpose only.

Positive Voices is a unique survey of the lives and experiences of people living with HIV in England and Wales. Between January and September 2017, people were randomly sampled from 73 HIV clinics and invited to take part in a survey issued by Public Health England. Over 4,400 people completed the survey, which was more than half of those asked.



**About 1 in 20 of all people who are living with HIV in England and Wales completed the survey**

The survey asked about: health and wellbeing, non-HIV health conditions and medications, experiences with healthcare, met and unmet needs, sex and relationships, lifestyle issues, and financial security. The questionnaire was designed in collaboration with people living with HIV, academics, clinicians and NHS commissioners. PHE has provided data for the report, but does not necessarily endorse the content expressed within.



## **CHANGING PERCEPTIONS**

Changing Perceptions is a community-led project, shaped and guided by people who responded to the Positive Voices survey.

Through workshops, a large and diverse group of people with HIV shared personal experiences and directed the Positive Voices data analysis. The result is a series of reports and a web resource that aim to change perceptions about living with HIV. The project is supported by Positively UK, National AIDS Trust (NAT), Watipa and researchers from Public Health England.

## **WHAT DO WE MEAN BY ATTITUDES?**

What people think and feel about HIV is influenced by a broad range of factors, including fear of transmission, preconceptions about lifestyle, and judgements about how HIV is acquired. Intersecting prejudices toward groups who are disproportionately affected by HIV (e.g. racism and homophobia) also have a negative impact. Unfavourable attitudes towards people living with HIV are referred to as stigma. HIV stigma can take different shapes and forms depending on the community and cultural setting. Preconceptions can also act as a barrier to testing and diagnosis if people are afraid of being stigmatised or if people are not offered testing because they do not fit the stereotype.



This report looks at the impact of preconceptions – who we talk to about HIV, the types of responses we receive, and how this affects our well-being.

# Our stories

## NO ONE THOUGHT THIS WOULD HAPPEN TO ME

Sara, aged 53, London



I became ill in February 2014. I suffered from food poisoning while in Burma and ended up in hospital. When I got back to England things did not get better. Eventually I was diagnosed with ulcerative colitis. The medication did not help and I kept getting worse. Finally, I was admitted to hospital in early 2015, nearly a year after I initially fell ill. They asked if they could do an HIV and hepatitis test. I said yes, not giving it a second thought.

A few days later, five people crowded around my bed to tell me I had HIV. I felt like my world was crashing down around me. It was a terrible shock.

I was told I would be moved to the Infectious Diseases ward. I anxiously waited, but I was never transferred. Throughout this time, lots of different healthcare staff came to see me; they would talk behind a closed curtain. I constantly worried about what other people in the ward could hear.

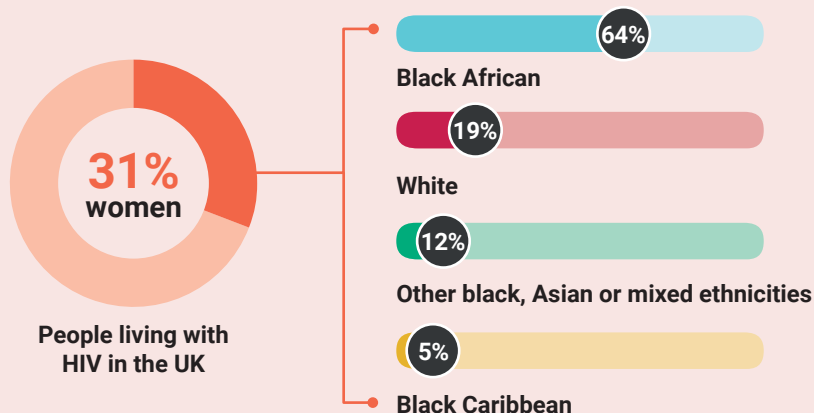
Shortly afterwards, the hospital sent a letter to my parent's address. When my parents read the letter, they learned about my HIV status. This did not go down well. I ended up having a nervous breakdown.

If I had been diagnosed sooner, perhaps it could have saved me some struggle, and some pain. But as a white, middle aged, upper middle class, educated woman, no one thinks that I could have HIV. My GP said honestly that she never would have thought to give me an HIV test. But HIV is not selective.

I think that there are misconceptions around people living with HIV in this country. There are so many women living with HIV, but we don't always hear about them.

I have felt very isolated and alone since my diagnosis and found it very difficult to find any support, especially in my demographic. It has been so much easier to find support for my other conditions: ulcerative colitis and diabetes. I often feel unsure about how HIV relates to my other health conditions."

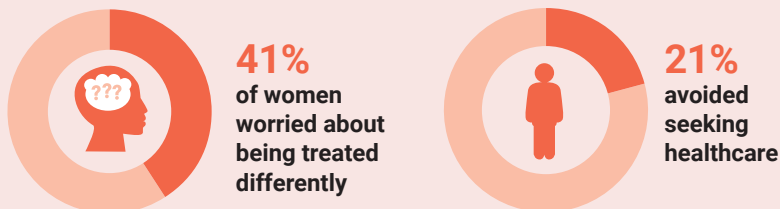
- Although some groups are disproportionately affected by HIV, there are people from all backgrounds living with HIV in the UK. One in 3 people living with HIV in the UK are women, of which 64% are black African, 19% are white and 17% are other minority ethnicities.



- Women living with HIV are often concerned about other's responses to hearing about their HIV status. One in 6 (16%) women said they had not shared their HIV status with anyone outside of a healthcare setting, compared to 1 in 9 (11%) men.



- Women do not necessarily feel safer in a healthcare setting; 41% reported feeling worried about being treated differently to other patients in the healthcare setting and 21% of women have avoided seeking healthcare when they needed it.





## STAYING DETERMINED AND OPTIMISTIC

Storm, aged 42, Brighton



I have been HIV positive for 18 years and consider myself very lucky to have always been surrounded by supportive, understanding and non-judgemental people.

When I was in a car accident, however, I was dismayed and shocked by some of the questions I was asked. The trauma surgeon asked how I acquired HIV while doing his risk assessment for performing spinal surgery. I refused to answer and questioned how it was relevant. I was then told it was too risky to operate on me.

Bringing my ARVs [HIV medication] with me into hospital has made me worry about stigma. When I had my accident, I missed four days worth of medication. The weekend hospital pharmacy and duty doctors could not confirm that I should be taking the ARVs I had with me. It is frustrating having to repeatedly explain the importance of treatment adherence to medical professionals – I feel ignored because I'm the patient not the expert.

I've always considered myself a determined and optimistic person, a rock for the people around me. I always try to see the good in any situation. But, I've had a really challenging time. My partner is dealing with a difficult long-term condition, I lost my job, my business failed, I lost my best friend, and I became disabled due to degeneration of my spine following my accident. I finally spoke with my GP and asked for help.

After two failed (lost or ignored) referrals to the wellbeing service, I finally received a telephone call to assess my situation. I admitted for the first time just how hard I was finding life. This phone call resulted in a letter confirming that I was extremely anxious and seriously depressed. It highlighted that I felt the world would be 'better off without me' and suggested that I would benefit from one-to-one counselling. The letter then thanked me for using the service and attached a general list of organisations I could 'self-refer' to if I wanted to speak to someone about my situation. I'm not sure what's worse about this, the outcome or the fact it took 9 months to get it. But I am determined to get the support that I need."

- HIV stigma still exists in the NHS. One in 9 (11%) people living with HIV in the UK have been refused healthcare or delayed a treatment because of their HIV status. HIV is a protected characteristic under the Equality Act 2010 and differential treatment based on HIV status is illegal discrimination. Despite this, discrimination persists.



**11%** reported being refused healthcare or delayed a treatment due to HIV status

- In addition to experiences of discrimination in the healthcare setting, issues around pain and discomfort, anxiety and depression, and mobility and self-care can greatly affect people living with HIV and can further exacerbate experienced and perceived stigma. 16% of people reported at least some problems with mobility and 40% said they have ever been diagnosed with a mental health condition. On any given day, 1 in 4 people with HIV report feeling anxious or depressed.



**16%** have at least some problems with mobility



**40%** have ever been diagnosed with a mental health condition



**1 in 4** reported feeling anxious or depressed on any given day



*One of the doctors said to me 'I'm sorry to hear about your illness I wouldn't wish that on my worst enemy'."*

GLEN 54



## GAINING STRENGTH THROUGH THE LOVE AND SUPPORT OF OTHERS

Mary, aged 45, London



I discovered I was positive when I went for a routine test at a charity I wanted to volunteer for. I was devastated. I had the courage to call two friends of mine and one told me she herself was positive. My friends were such a source of support for me during this hard time; another took me for a confirmation test and helped me register with an HIV clinic, all along offering kindness and support.

After my diagnosis, I stopped looking for a relationship because I feared the stigma and discrimination I would face. After about 6 years, I went to a party and met a nice guy that I fancied. I was torn between letting him go or letting him know.

I sent him a message informing him about my status – at first, he thought I was lying. But once I told him it was true, he told me he still wanted me regardless of my status and we dated for over 5 years. I was undetectable for the entire time we were together and was taught at the clinic that there is not risk of HIV transmission if I am undetectable (U=U). He knew that I had an undetectable viral load and never showed any fear of getting infected. Even though we are no longer dating, he has always been supportive.

After we separated, I met another guy, but sadly my HIV status was not as well received this time. This new guy and I were never intimate, we never even kissed or held hands, yet when I told him about my status, he was furious I didn't tell him sooner and he never contacted me again.

I never told any member of my family and I don't intend to in the near future, not because they will discriminate or stigmatise me, but because they will feel sorry for me and think I will die soon. People are still living in the dark about HIV and don't realise that people living with HIV can live a happy and healthy life."

- Nearly 1 in 3 (31%) women living with HIV reported needing help sharing their HIV status with others, compared to only 1 in 5 (20%) men.



**1 in 3**  
women

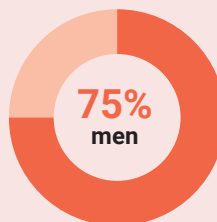
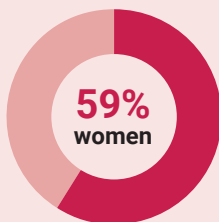
**People who  
needed help  
sharing their  
HIV status  
with others**



**1 in 5**  
men

- Only 7% of women who have a main partner did not know their partner's status; this was much lower for men (2%).

**People who  
shared their HIV  
status with their  
main partner**



*I have a fear of disclosing my condition outside the HIV clinic, so although I need peer support and social contact. I have never felt brave enough to try and get it."*

**NOMUSA, 39**

- In the Positive Voices workshops, women who were mothers reported that sharing their HIV status with others was challenging because they not only fear being stigmatised themselves, but that their children will also be stigmatised.



*It's the fear of being seen different and not a good way or judged because of my HIV."* **BETUNDE, 23**

## FOCUSING ON MY FUTURE

Alexander, aged 49, London



I grew up in the 80s with the emergence of HIV as an issue; but I had no idea it would have a direct impact on me. Back then I had a laissez faire attitude towards relationships and the women I was with. I wasn't cautious because I thought HIV only affected gay men, drug users or people that came in contact with those people. It was a very African belief.

Sometime in the early 2000s, I felt weak, breathless and generally pretty incapacitated. I couldn't understand why, but I lost a lot of weight and was lethargic. One day I was rushed into hospital and found to be close to death. It was then that I was diagnosed.

My initial reaction was that I was in good hands. There were no tears and no time for regret. The diagnosis actually had a positive effect on my life. It gave me direction. I felt empowered to take control of myself both physically and mentally.

But one issue I had was around telling people. I had become a Muslim 15 years before my diagnosis. In this community, HIV is a taboo subject. It's not so much actively stigmatised, but it's stigmatised by silence.

I was also concerned about telling my family. It was several years before I disclosed to a family member. They then disclosed to other people in my family without my consent. The reaction I got was really fantastic though. They assured me that I was still their son, their brother, just now I had a 'minor medical condition'. Their love for me has not and will not diminish because of HIV. I was alive.

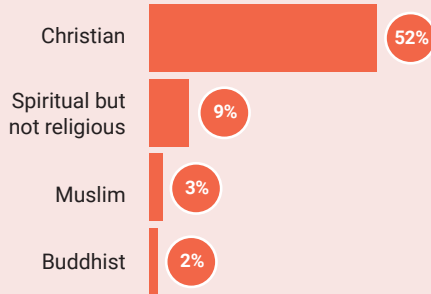
Before I accepted Islam, I drank and socialised with women. I was reckless, and I enjoyed it. When I became a Muslim, I stopped living that life. Elements of that life crept back in over time, however. When I was diagnosed, I changed again. In relationships with women, I was both physically and emotionally detached. I sought help and through therapy, I've rediscovered myself. I feel human again where I had felt dehumanised by HIV.

The diagnosis gave me focus. Islam is a disciplined faith, and the things I need to do to keep myself healthy in respect of my HIV also need discipline. The two things work well together in my life. That focus is now on the future. I'm now

married. Making a decision to commit was hard, but one that I am proud of. It is a positive decision for many reasons, and I consider it my highest achievement. My HIV is part of that, not a barrier to it.”

## POSITIVE VOICES INSIGHTS

- 70% of people living with HIV were religious or spiritual, of which 49% say their religion was very or fairly important to them. Most (52%) are Christian, while 9% are spiritual, but not religious, 3% are Muslim and 2% are Buddhist.



“Once you are diagnosed with HIV, your self-esteem goes down, your activities decline and I feel that you really need psychological, social and spiritual support, for your well-being.” LINDIWE, 55

- Adherence to HIV treatment did not differ among those who were religious and those who were not. However, 18% of people who said religion is very important to them have not shared their HIV status with anyone, in comparison to 10% among those who said religion was not important to them.

### Proportion of people who have not shared their HIV status



Religion very important



Religion not important

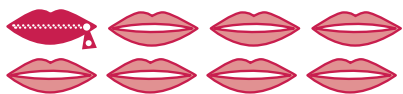
# How people think and feel about HIV

## TALKING TO OTHERS ABOUT HIV

When it comes to telling people about HIV, no two experiences are the same. HIV is still a highly stigmatised condition and for many people living with HIV, talking to others about their status is a significant step. This can be because of concerns about how other people perceive HIV, fear of rejection, or not wanting to worry others.

The word 'disclosure' is commonly used to describe the process of telling others about one's HIV status. Using this word can amplify the difficulty, as it implies that what is shared is something negative, a secret that needs to be guarded. Throughout this report we use 'talking' or 'sharing' as this is more empowering and less stigmatising.

In the Positive Voices survey, 1 in 8 (13%) people said that they had not told anyone about their HIV status other than healthcare professionals. While some simply may not feel the need to talk to others about HIV, for others this could contribute to significant loneliness and isolation, especially if it is a barrier to forming relationships with others.



**1 in 8** said they had never told anyone about their HIV status outside of a healthcare setting



**1 in 5** people reported that they needed help with loneliness and isolation in the past year

Our stories highlight the importance to our well-being of being able to talk to friends or family about HIV. Some people were very selective about who they talked to about HIV, while others were able to be open about their status. What is important is that the decision to tell other people is taken by the person living with HIV. When this agency is removed by a breach of confidentiality, it can cause significant distress. There are times when we do not feel confident or safe talking about our status, especially if we suspect that the response will not be a supportive one.



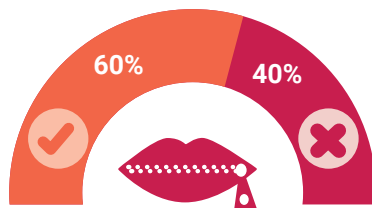
*I don't feel comfortable telling anyone about my HIV. Very difficult in general but far worse in the Asian community/ culture (ashamed to even tell my family).” HAMZA, 43*

The importance of strong HIV support services is clear. Support services, including peer support, can help people to prepare for and feel comfortable about telling others about their HIV status. This can take the form of sharing or listening to other people's experiences, or supporting people to deal with internalised stigma before telling others and then managing any negative reactions.

Overall, around 1 in 4 people with HIV said that they needed support disclosing their status in the past year – this need was unmet for 40% of people.



**1 in 4** reported needing help sharing their HIV status with others



**Met and unmet need for help with sharing an HIV status with others**



*In the work place, in the gay community there is still so much stigma. People now ask if I'm clean.” FORD, 43*

Women living with HIV were more likely to tell family than friends about their HIV status. A significant proportion of women living with HIV are from black African and Caribbean ethnic communities and/or migrant communities where HIV stigma is common. This illustrates why support services that offer opportunities to discuss HIV safely can be so valuable to women. 95% of women said HIV support services said they were moderately or very important to them (90% of men said the same).

Nearly a third of women (31%) said they needed support with sharing their HIV status with others in the past year. This need was unmet for 29% of them.

### WHAT NEEDS TO BE DONE?

- All people living with HIV should have access to HIV focused support services, including peer support. The government must clarify statutory responsibility for funding these services and local commissioners must work together to ensure access.
- HIV specialist support should be retained locally both to meet needs which generic services are unable to provide appropriately (for example peer support), and also to complement, train and work alongside generic provision.

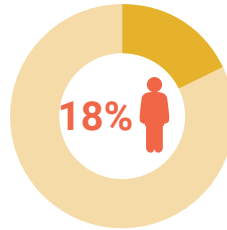


## EXPERIENCES OF STIGMA IN HEALTHCARE SERVICES

More than half (55%) of people with HIV said that in the last year they had used a sexual health clinic, 52% used a dentist, 20% used Accident and Emergency (A&E) services, and 11% used inpatient services.

Across the range of different healthcare services used by people with HIV, stigma was reported across in of them. One in 3 (35%) had been worried that they would be treated differently to other patients, 14% had actually experienced discrimination in a healthcare setting, 18% had avoided healthcare when they needed it, and 11% of people living with HIV had actually been denied or refused a treatment or procedure that they needed.

**1 in 3** worried that they would be treated differently to other patients

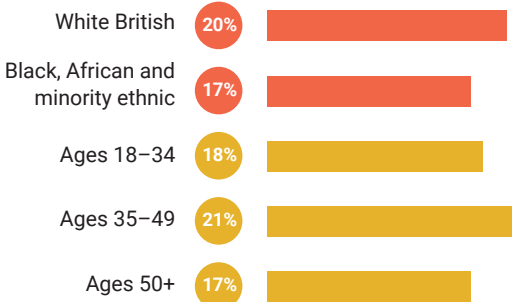


**Proportion of people with HIV who avoided healthcare when they needed it**



*At a GP visit, assumptions were wrongly made about the cause of a healthcare problem due to being gay and having HIV. GP was biased towards a STI, but it wasn't this." CALLUM, 33*

**Discrimination was experienced at similar levels by people for all ethnicities and ages**



**1 in 10** had actually been denied or refused a treatment or procedure that they needed



## WHAT NEEDS TO BE DONE?

- All NHS services should treat people living with HIV with dignity and respect so that we feel safe and can participate in our care. Local and national commissioners and NHS leaders must have zero tolerance for HIV stigma and discrimination.
- NHS leaders should ensure that all NHS staff are trained on HIV and are linked to local HIV expertise and services. Training should include awareness of stigma, transmission routes and U=U.
- Care providers must place people with HIV at the centre and provide services across a well-integrated system that we feel safe and confident in using.



“

*In February 2015 I was a hospital inpatient due to having an ectopic pregnancy. I had to wait for many hours to be assigned a bed, not because there weren't any, but because they were waiting to give me an isolated room... I had the feeling that I was being treated differently by some nurses and clinical support workers due to my HIV status.” ADAKU, 32*

“

*I have not experience any discrimination from healthcare professionals. Only my wife and GP and HIV specialist know about my status. I have not told anyone else due to fear of discrimination.” PETER, 56*

“

*The dentist asked me to make my appointment at the end of the day because of my HIV. At the fertility clinic in St Albans the nurse questioned me wanting to conceive considering I have HIV.” SIAN, 43*





*I was fortunate that when I returned from abroad that I got a job in London and benefitted from the excellent support and services from Dean Street. I am certain that without the specialists and facilities that were provided I would most likely have taken my life as the stress of the diagnosis and my inability to tell anyone is a crushing burden...*

*This [support] is especially important for those for whom religiously or culturally the shame of a diagnosis means they will not seek out help... or for those persons who have more than just a positive diagnosis to deal with."*

**CRAIG, 35**



# Find out more

Visit [www.changingperceptions.co.uk](http://www.changingperceptions.co.uk) to find out more about:

- How people with HIV were involved in this report
- Findings from the Positive Voices survey
- Stories from those who took part
- Changes we want to see
- How this data is being used to create change

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

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

**Public Health England** is an executive agency of the Department of Health and exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. To find out more visit: [www.phe.gov.uk](http://www.phe.gov.uk)

**Watipa** is a social enterprise working to enable equal societies, just development, and equal health for all. It provides inter-disciplinary consultancy services in public health and international development, and channels the profits into educational scholarships for young people in developing countries. To find out more: [www.watipa.org](http://www.watipa.org)



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