



Changing
Perceptions

Talking about HIV
and our relationships

PositiveVoices
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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Photography by Mareike Günsche/Aspectus

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.

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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 with an undetectable viral load also means that people cannot pass the virus on to others – this is known as undetectable=untransmittable, or U=U. Nevertheless, society's knowledge and attitudes have not kept pace with these developments. There are widespread misperceptions about HIV and for many people living with the HIV the problems long associated with HIV, such as discrimination, poverty, stress and isolation, remain as challenging as ever.

As medical advances have transformed HIV from an acute, often fatal infection, to a chronic condition, HIV care and support services must also adapt to remain relevant and accessible.

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.

This report covers three different aspects of relationships and HIV: sharing our HIV status with others (also known as disclosure), intimate relationships and sex in the era of U=U, and relationships with healthcare providers.

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 RELATIONSHIPS?

Our relationships with other people are an important part of who we are. In this report, relationships include those with friends and family, with romantic or sexual partners, as well as with people who are involved in our healthcare, such as GPs and clinicians.



There were a number of questions in the Positive Voices survey that provided an insight into relationships, their importance and the impact they have on our quality of life, for example:

- Who have we told about our HIV status?
- Do we have a main partner? How close are we to this person?
- Do we have condomless sex with our partner/s?
- Did we need and/or access advice on relationships, sex life, family planning, conception, and telling people about our HIV status?

Our stories

LIVING OPENLY POSITIVE

Rose, aged 55, London



I am a black British and African heterosexual woman. I am the mother of two and have two grandchildren. I was diagnosed with HIV in 1995 in Tanzania. In April 2003, I came to the United Kingdom for further education. I was determined not to let my HIV status hinder my ability to study, to work, to marry and to live a normal life like others. I completed my MBA in 2006.

I got married in 2007. My husband was HIV negative, but he knew about my HIV status, so we started off using condoms. After one year of our marriage, he refused to use condoms anymore and, as a woman, I did not have the power to negotiate condom use. According to my culture, I can't say no if my husband wants sex.

I informed my HIV consultant about our unprotected sex. She told me that, provided I have disclosed my status to him, it was his responsibility to take care of himself. At the time I didn't know that undetectable is equal to untransmittable (U=U). I think that U=U is very empowering for other women to know about, especially if they lack the power to negotiate safe sex.

My husband also took advantage of my finances. He forced me to pay his way for many things, ranging from basic financial obligations to airfare for holiday travel. In order to be free from his sexual and financial demands, I decided to divorce him in 2011 and have been strong and independent ever since.

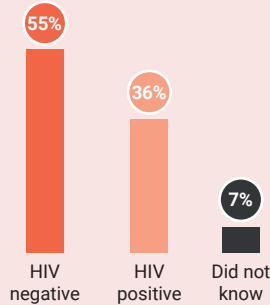
Counselling gave me the confidence to be open about my HIV status to my employers, my friends, and my family members, including my children. Everyone is very supportive. I feel that sharing my status with others has helped me to fight stigma – it forces me to be more open about what living with HIV really means.

To avoid being lonely, I attend an HIV support group in my local area where I learn, exchange ideas and share experience with others. I have a good relationship with my HIV consultant and clinic, my GP, my dentist and local hospital. They all know my HIV status. I am very proud of knowing my HIV status and living positively and I hope that by sharing my story, others can be empowered to live openly positive as well."

- More than half (57%) of women with HIV were in a committed relationship (i.e. with a partner or spouse), of which 55% had HIV negative partners, 36% had HIV positive partners, and 7% did not know their partner's HIV status.



57% of women with HIV were in a committed relationship



HIV status of these partners

- In most cases, women said they were close to their partner. However, 1 in 10 women stated they were not and this was most commonly reported among older (aged over 50 years) women and African-born women.

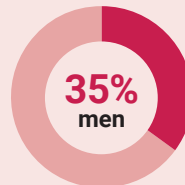
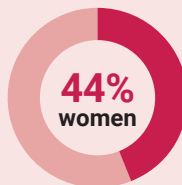


1 in 10
women were not close to their partner



- Women may especially benefit from HIV support services, including peer support. These services can provide supportive spaces where women feel safer talking about HIV than within their communities where HIV may be stigmatised, and can build confidence to tell others about their HIV status. Women were more likely than men to have used HIV support services (44% vs. 35%) and nearly all said that the support they received had been important for their health and well-being.

Proportion that have ever used HIV support services



OPENING UP TO THE POSSIBILITY OF RELATIONSHIPS IN THE FUTURE

Ben, aged 65, Yorkshire



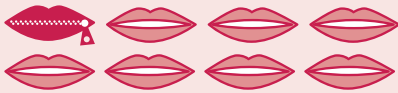
I was very ashamed and worried about whom I should tell about my HIV status. When I was diagnosed I was single with two teenage children. I didn't want them worrying, so I decided not to tell them. My only other close living relative was my younger sister, who herself was going through a very difficult time, so I didn't want to tell her either. I told no one. I felt completely alone and isolated.

In my mind, having HIV meant that I would be single forever. The thought of passing on my HIV to someone else terrified me. The idea of sharing my status with someone as a prelude to a relationship was something I didn't feel I could do.

Every now and then, I would have a sexual urge, but because I was reluctant to tell anyone about my HIV, all I could do was have anonymous, casual sex with partners I hoped I'd never see again. Even though I took all the appropriate precautions, I was always worried... what if the condom broke? These experiences were therefore emotionally empty and ultimately unsatisfactory – but this seemed like the better option than telling someone about my HIV status.

Now, the news that undetectable equals untransmittable (U=U), is such a relief! It has taken so much of the anxiety away from me. I feel as though a huge weight had been lifted from my shoulders. I now feel much more confident talking about my HIV with someone, especially as U=U becomes more widely known and understood. I no longer feel like I am seen as a threat to someone's health. U=U is a real game-changer for me as I approach future relationships. The door is now at least ajar, if not wide open."

- Navigating sex and telling existing or potential partners about our HIV status can be difficult due to fear of rejection, feelings of shame, and anxiety about passing on HIV. One in 8 (13%) people with HIV said they had never told anyone their HIV status outside of a healthcare setting – this is significantly higher among black Africans and other people of non-white ethnicities, and people aged over 50.

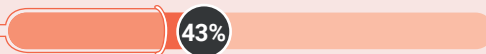
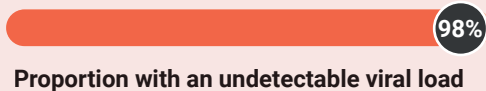


1 in 8 said they had never told anyone about their HIV status outside of a healthcare setting

- The proven science behind U=U – the inability to pass on HIV with an undetectable viral load – allows people with HIV to have condomless sex without worrying about passing on HIV. This can be empowering, but not everyone is aware of or understands this message.
- Four in 10 (40%) people with HIV reported that they were not sexually active (i.e. abstinent) in the past 3 months.
- Of the 60% of people with HIV who were sexually active, 98% had an undetectable viral load and 43% used condoms during sex all of the time, even in monogamous relationships.



4 in 10 were not sexually active in the past 3 months



Proportion who said they used condoms all of the time



It would make a difference if people knew much more about HIV. For example that you might be perfectly able to have sex without condoms depending on your viral status.” ANGELIQUE, 43

REALISING MY WORTH

Sima, aged 48, London



I am a 48 year-old British born Asian woman who has been living with HIV for 16 years. At the time of my diagnosis, I never thought this would be something that would happen to me!

A year prior to my diagnosis, I was in a one-year relationship and I had suddenly started losing weight. My hair had changed from curly to straight. I had a constant cough and always felt exhausted.

The blood test results from my GP identified unusual white blood cells, so I was referred to the haematology department. After six months of investigations, they suggested exploring stem cell research. It was only then that I had an HIV test and was diagnosed. It was a total shock. At the time I felt I could not share my diagnosis with anyone because of the stigma and shame I would feel.

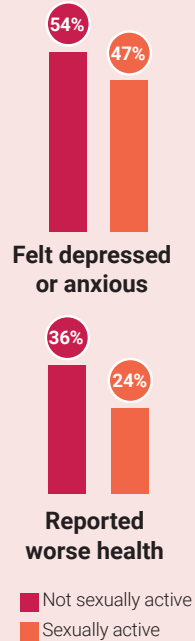
My brother was the first person I told and he was very caring and understanding. My other siblings and I decided not to tell our elderly parents to protect them from the cultural stigma around HIV. They were told I had pneumonia and later I told them I had a rare blood condition for which I had to take medication.

The diagnosis had an impact on my relationship and I was not able to be intimate with my partner as I had lost my libido and self-esteem. We split up amicably after four years and we are still good friends.

In the past I held a strong belief that I would not be able to find a partner that would accept me with my diagnosis. But I was proven wrong. The next guy I dated accepted me for me and it lifted my confidence. Whilst my relationships over the years were short lived and included a few rejections along the way due to my status, I learnt about my worth and that I am more than my HIV label. Since the Undetectable=Untransmittable message has come out, I have been even more empowered because it helps me explain to my partners that I have an undetectable viral load, and therefore I cannot transmit HIV or infect them.

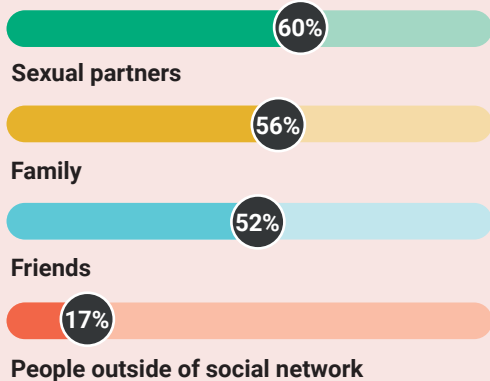
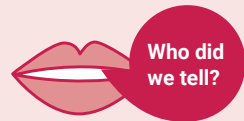
The biggest issue I face is shifting negative mind sets about HIV and clarifying misconceptions. I have been a peer mentor for the last five years. I strive to help change the perceptions of the powerful women I have supported, to help them build resilience, and to help them recognise that they are more than their HIV status.”

- Interest in sex can change after an HIV diagnosis – sex drive can disappear, reduce or even get stronger. These changes in our libido may be temporary or fluctuate over time and can worsen underlying problems such as negative feelings about having HIV and ultimately impacting on our quality of life.
- Compared to those who were sexually active, people who were not sexually active were significantly more likely to report feeling depressed or anxious, and more likely to report worse health.
- Partly because of the stigma around HIV, many of us consider carefully who we want to tell or know about our HIV status. Of the 87% of people who had shared their HIV status with others, people most commonly reported telling sexual partners, followed by family and friends. Only 17% of people shared knowledge of their HIV status outside of the immediate social network, such as neighbours or co-workers.



“When I inform people I am HIV+, they shy away. It is very difficult to make friends or relationships due to HIV.” RUPERT, 53

87% people with HIV disclosed their HIV status to others



GETTING THE BEST FROM RELATIONSHIPS WITH MY HEALTHCARE TEAM

John, aged 61, Surrey



I have known about my HIV status for 17 years now. But, having heard about hardships my friends living with HIV faced, I decided I needed to educate myself about my long-term conditions and medications. I wanted to understand how to keep well and live a full life.

I have learned so much about my medication and potential interactions with my HIV treatment, which is important because there is a void of knowledge outside specialist areas. I have the greatest admiration for the specialist pharmacists and my HIV consultant has been brilliant, providing me with great reassurance. My HIV clinic has a fantastic team.

At an early stage, I gave permission for my HIV consultant to write to my GP. I am delighted I did as my GP team is also great – but this did take some education from me. When I joined a big local practice, the nurse asked me if I had any health conditions and I informed her I was living with HIV and hepatitis C. Once I had picked her up off the floor she said to me “Well you look fit and well today so I think you should make an appointment to see the GP soon so he can see you whilst you’re well and not when you’re ill.” This interaction made me realise the importance of breaking through the stigma.

When I saw my GP for the first time, what should have been a 10-minute appointment turned into a 45-minute coaching session where I educated him about HIV and hepatitis C. But it was valuable time spent and was the start of a great GP/patient relationship.

I may have other conditions to manage, but I still exercise and socialise. I don’t particularly like being described as a patient. However, I recently was introduced by my HIV pharmacist as an ‘expert patient’ and that felt good. As an expert patient I embrace my own health and wellbeing. I focus on building strong relationships with my consultants, pharmacists and GP. I call it taking a pro-active approach to health and wellbeing.

My journey hasn’t been straightforward, but I have been determined to embrace any challenges that come my way. Finding a friend with whom

I can speak has helped me focus on the journey, rather than worry about the past. HIV has made me more fearless. I have already lived longer than I was expecting. In addition to HIV, I have been cured of cancer and cleared hepatitis C. Now, I am ready to face anything else that is thrown my way.”

POSITIVE VOICES INSIGHTS

- Nearly three-quarters (73%) of people living with HIV rated their health as good or very good. Even among older people living with HIV, many maintain good mobility, practice self-care and are able to do their usual activities. For these reasons, many people living with HIV may present to their GP as fit and in good health.
- Over 95% of people with HIV agreed that they are able to self-manage HIV and say they have enough information about HIV.
- Satisfaction with HIV specialist services is extremely high, but this is not always reflected in other healthcare settings. While the majority (94%) of people with HIV have disclosed their status to their GP, only two-thirds (64%) felt that their GP knows enough about HIV and HIV treatment, and even fewer (59%) were comfortable asking their GP questions about HIV.



People with HIV who have told their GP



Agreed that their GP knows enough about their HIV condition and treatment



Felt comfortable asking their GP questions about HIV

“The belief that the GP is going to be the magical creature who manages all of your conditions is a myth. That person is you. You will have to self-manage.”

LOUISE, 41



People with HIV reported a high level of satisfaction with HIV specialist services

HIV and relationships

Meaningful, authentic and honest relationships can make a real difference to health and well-being, and improve quality of life. Forming relationships is fundamental to us, as it is for all people. This includes not just relationships with friends, family and partners, but also with those that support and care for us, such as advocates, peer mentors and healthcare professionals.

SHARING OUR HIV STATUS WITH OTHERS

Whether to talk about our HIV status is usually a careful decision. Not everyone feels that HIV is something they want or need to talk about. But, for some it is important to be able to share the experience of living with HIV with family and loved ones; to feel closer, be heard and get support and advice if and when it is needed.

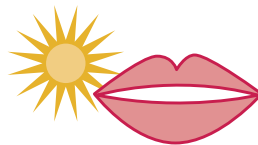
For some, feelings of shame, fear of rejection, and self-stigma can add anxiety around forming new relationships. Especially if we have previously faced rejection or judgement related to HIV, as this can cause or exacerbate negative feelings. Loving and accepting relationships are crucial in counteracting this.

“ I don't feel comfortable telling anyone about my HIV, I am ashamed even to tell my family. It is very difficult in general, but far worse in the Asian community.” MAHMOUD, 43

In the survey, 87% of people said they had told a friend or loved one about their HIV status. But 1 in 8 (13%) had never told anyone about their HIV status outside of a healthcare setting. Those who had shared their HIV status, even with just one person, reported improved quality of life and mental health compared to those who had not.



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



Sharing with even one person, improved quality of life

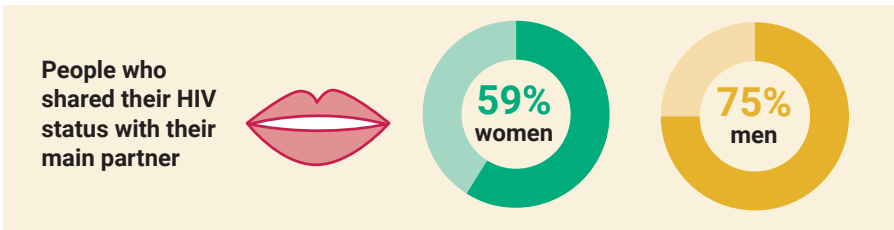
“ I have not been discriminated against, but I am fearful of it, hence I disclose my status sparingly – never at work, never with friends, but selectively with medical providers.” RAYMOND, 60



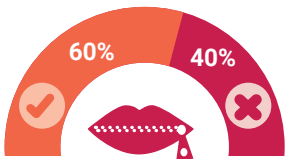
I used to be afraid what people may think if they found out I have HIV. Now I am no longer afraid or ashamed. I am ready to speak about my HIV.” BHAVNA, 70

In many cases, people encountered positive responses from sharing their HIV status, but this was not always so. There were examples where people were unsupportive; this can be very distressing and may make it more difficult to open up to others in the future.

Compared to men, women were less likely to have told their partner about their HIV status. In heterosexual relationships where power is skewed towards men, discussions around sexual health and HIV status may be more difficult. Some women may not feel safe saying they have HIV for fear of a negative response including emotional abuse, threats and violence. Some may simply prefer not to tell their partner as they do not feel that they need to know.



1 in 4 reported needing help disclosing their HIV status



40% of this need went unmet

One in 4 people with HIV said they needed help disclosing their HIV status in the previous year: this was higher in women (31%) compared to men (21%). Of those who needed support with this, 60% said they received it but 40% did not. In most cases this was because the person did not try to get this help, suggesting that some people are not aware that such support exists. HIV support services, including peer support, can provide spaces where people can talk openly about their HIV status, share advice and encouragement around telling others.



My status is pretty secret because, although I know I am undetectable, people that are not HIV savvy will discriminate.” ANJA, 35

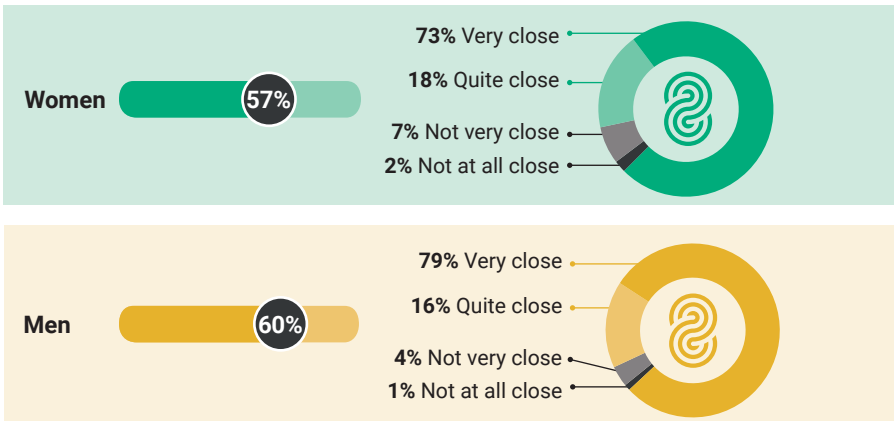
ROMANTIC RELATIONSHIPS, SEX AND SEXUAL HEALTH

Sex and intimacy are a natural part of our lives. We have a right to enjoy sexual pleasure. Yet fear of rejection and anxiety about passing on HIV can prevent us from forming new sexual relationships or feeling close to a current partner. This can lead to loneliness, isolation and depression, and poor health.

Negative feelings about HIV and associated low self-esteem and self-stigma may also be exacerbated by power imbalances in an intimate relationship when one of us is living with HIV and the other is not. Overall, 2 in 5 (42%) people with HIV had a main partner¹ – over half (57%) were HIV negative, 39% were HIV positive, and in 4% the HIV status was unknown.

Reported having a main partner

Closeness to main partner



Gender inequality can affect how women living with HIV experience intimate relationships. In the UK, 4 out of every 5 women living with HIV are migrants and 2 in 3 are of black African ethnicity. Women are more likely to be in care-giving roles and to be in circumstances where they are not financially independent or lack power in their household or relationship.

Women living with HIV are at increased risk of gender-based and intimate partner violence, and this has been shown to negatively affect adherence to treatment, ability to negotiate sex, and healthcare access.²

1. Defined as "The person you feel committed to above anyone else. This is a person you would call your partner, spouse, girlfriend/boyfriend, or husband/wife".

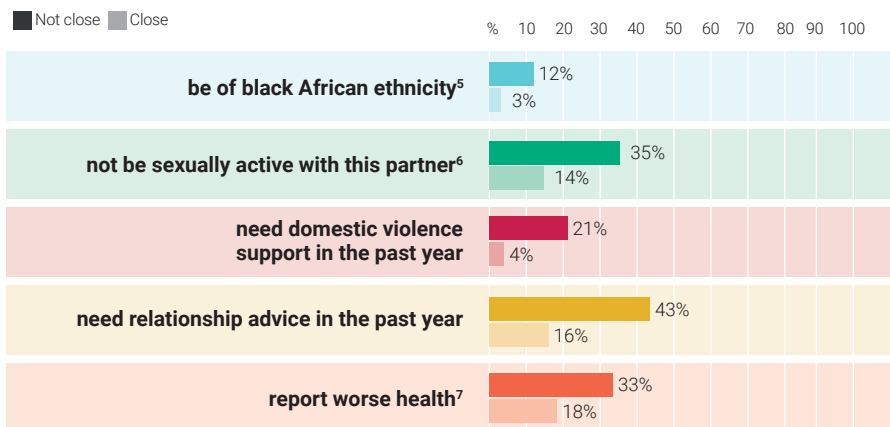
2. Dhairyawan R, Tariq S, Scourse R, Coyne KM. 'Intimate partner violence in women living with HIV attending an inner city clinic in the UK: prevalence and associated factors'. *HIV Med.* 2013 May;14(5):303-10.



One in 16 (6%) of women reported they needed support for domestic violence in the past year. Furthermore, studies on older women have shown high levels of problems with libido, pain during sex and other sexual dysfunction.³ In contrast, gay and bisexual men reported high numbers of casual partners and higher rates of sexually transmitted infections (STIs). Therefore, it is important to explore romantic relationships and sex by gender and sexual orientation.

WOMEN

- The large majority of women identified as heterosexual (97%), while 2% identified as bisexual and 1% as lesbian, asexual or other.
- Over half (57%) of women said they had a main partner. 55% had HIV negative partners, 36% had HIV positive partners, and 7% did not know their partner’s HIV status. Women were more likely to not know their partner’s HIV status (6%) compared to heterosexual men (3%) and gay and bisexual men (2%).
- Of those with a main partner, 1 in 10 (10%) reported they were not close⁴ to this partner. Compared to women with close main partners, women who were not close to their main partner were significantly more likely to:



3. Tariq, S. on behalf of the PRIME Study Group (2018), *Menopause in women living with HIV in England: findings from the PRIME Study*.

4. Defined as “Not very close” or “Not at all close”.

5. Compared to women of white British ethnicity (2.6%), other white ethnicity (4.0%) and women of other black and Asian minority ethnicities (3.2%).

6. Defined as “No sex with main partner in the preceding 3 months”.

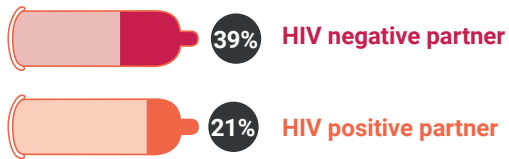
7. Self-rate health status as “Fair”, “Poor” or “Very Poor”.



I received discrimination about my status from my ex-partner every time we would argue. He used to put me down saying bad things about my HIV status.” PRECIOUS, 23

- Almost half (46%) of women had condomless sex with their main partner in the last 3 months: this was consistent across all age groups and ethnic groups. Women whose partner was HIV negative were more likely to use condoms (39% all the time and 20% sometimes) compared to women whose partner was HIV positive (21% all the time and 22% sometimes).

Proportion of women with HIV who used condoms all of the time with their main partner



- In the context of HIV prevention, people with HIV may use condoms to prevent transmission to partners. However, 98% of all women with HIV had an undetectable viral load and were therefore not at risk of passing on HIV. Women with HIV may continue to use condoms to prevent STIs or unintended pregnancy but outdated knowledge of HIV transmission risk may also be a factor.
- One in 4 (25%) women reported at least one casual sexual partner⁸ in the previous 3 months: usually (91%) only one partner was reported and these were nearly always men (98%). One in 3 (38%) had condomless sex with a casual partner. Viral suppression was high (98%) and not associated with whether women used condoms with casual sexual partners.



1 in 4 women reported at least one casual sexual partner in the previous 3 months



Proportion of women who had condomless sex with a casual partner



The GP said I had to tell my partner even though I am undetectable, or else I should not be in a relationship.” CLAIRE, 27

8. Defined as “Men and women you have had sex with, excluding a main partner if you have one”.

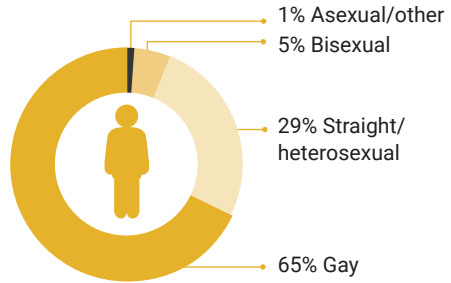
“ *The most important thing is to have a partner who supports you, as mine has for nearly 25 years. Particularly during the early stages when I was given 6 months to live and through the various drugs’ side effects. I can never reveal my HIV status to anyone other than my doctors and family as there is still a terrible stigma attached to having HIV.*” EDWARD, 69

MEN

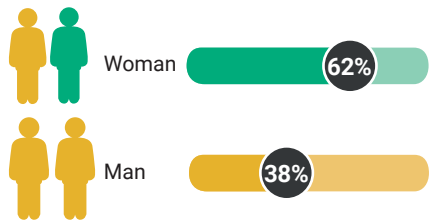
- Two-thirds (65%) of men with HIV identified as gay and a further 5% as bisexual. Three in 10 (29%) identified as straight/heterosexual; of these, 2% had sex with a man in the previous 3 months.

- Among survey participants, 72% of heterosexual men and 55% of gay and bisexual men reported having a main partner. 99% of gay men said their main partner was a man, 98% of heterosexual men said it was a woman. Among bisexual men, 62% said their main partner was a woman and 38% said it was a man.

- Compared to women, more men said they were close to their main partners. Fewer than 1 in 20 men (4.2% of gay and bisexual men and 4.4% of heterosexual men) felt they were not close to their main partners.
- Men rarely (2%) stated a need for domestic violence support, and this did not differ by sexual orientation, but it was more common among men that were not close to their partner (18% of heterosexual men and 4% of gay and bisexual men) as compared to men that were close to their partner (1.3% of heterosexual men and 0.1% of gay and bisexual men).



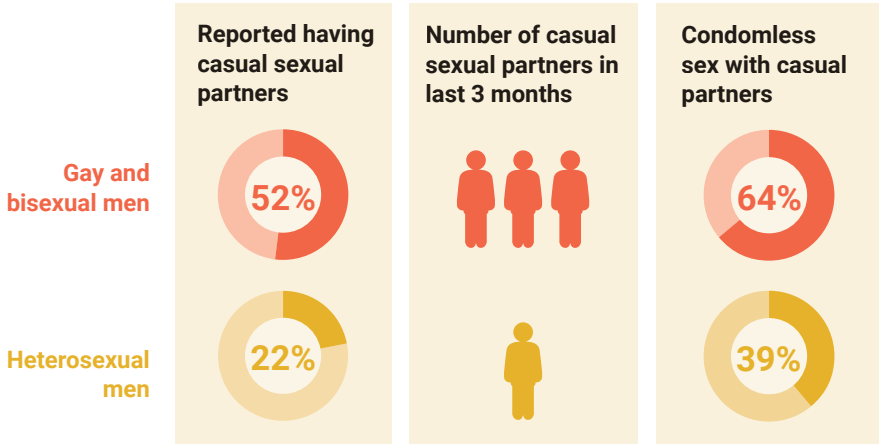
Men's sexual orientation



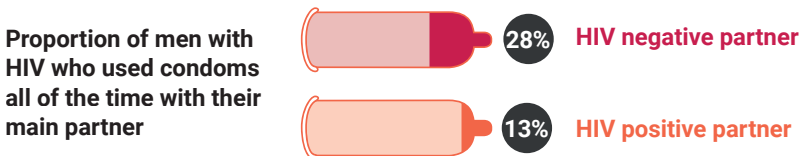
Gender identity of bisexual men's main partner

“ *With sexual partners, I always disclose my HIV status, however I have completely lost my confidence to try and get in a relationship fearing that I will be rejected by a partner as it has happened in the past. As a result of this I chose a lonely way for myself. I don't feel I can go through the rejection process again.*” SERGIO, 33

- On average, gay and bisexual men were more likely to report having casual sexual partners (52%) compared to heterosexual men (22%), a higher number of casual sexual partners (3 versus 1 in the previous 3 months), and condomless sex with casual sexual partners (64% versus 39%).

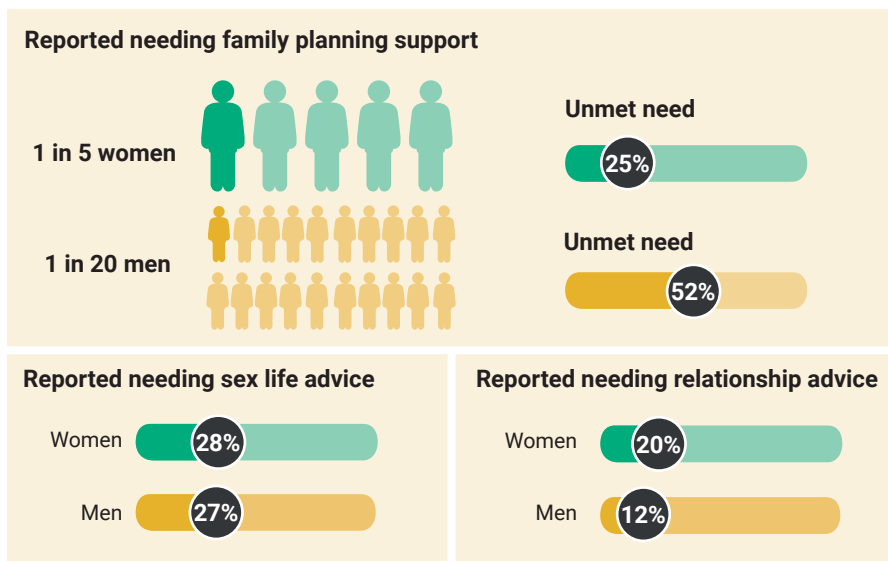


- As for women, 98% of men had undetectable viral loads and had no risk of passing on HIV. However, STIs – which are associated with condomless sex and multiple sexual partners – were more common in gay and bisexual men with 20% diagnosed with an STI in the previous 3 months, compared to 5% of heterosexual men and 4% of women.
- Heterosexual men were more likely to have an HIV positive partner (44%) compared to gay and bisexual men (36%).
- Of those with a main partner, 40% of gay men and 30% of heterosexual men had condomless sex with this partner in the previous 3 months. Men with an HIV negative partner were more likely to use condoms (28% all the time and 30% sometimes) compared to men with an HIV positive partner (13% all the time and 13% sometimes).



RELATIONSHIP NEEDS

People reported needing support around sex and relationships, some of which was unmet. One in 5 women and 1 in 20 men reported needing family planning support in the last year, of which 25% and 52% said this need was unmet, respectively. 28% of women and 27% of men reported needing sex life advice in the past year, of which unmet need was 24% for women and 47% for men.



1 in 5 (20%) of women and 1 in 8 (12%) of men reported needing relationship advice in the last year. This need was higher among both men and women who either do not have a main partner or are not close with their main partner.

HIV specific support services can be a key source of support for these issues. 44% of women reported they have ever used support services compared to 35% of men. Almost a third (29%) of those who use HIV support services said that they had been more difficult to access over the past two years.

In England, local funding for HIV support services was reduced by at least 28% from 2015/16 to 2016/17 (the actual reduction is believed to be higher but is difficult to calculate from the data available).⁹ In many places, charities have had to scale back their services, while others have closed altogether.

9. NAT (2017), *HIV support services: the state of the nations*.

UNDETECTABLE=UNTRANSMITTABLE (U=U)

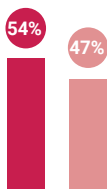
U=U means that people with HIV who have an undetectable viral load are able to have condomless sex without worrying about passing on HIV.

However, there have been and still are a lot of misconceptions about HIV transmission that contribute to stigma and fear. For some of us, feeling that we may be a risk to others contributes to low self-esteem. These feelings are sometimes referred to as internalised stigma or self-stigma. Half of people living with HIV reported internalised stigma in the 2015 UK HIV Stigma Survey.¹⁰

As a result, some people make the conscious decision not to have sex. Four in 10 (40%) people with HIV reported they were not sexually active (i.e. abstinent) in the previous 3 months: this was similar for both men and women. However, sexual abstinence was significantly higher (56%) among people diagnosed prior to 1996 (before antiretroviral medication was available), even after accounting for older age. A higher proportion of people who were sexually abstinent reported feeling depressed or anxious (54% vs. 47%) and reported worse health (36% vs. 24%).



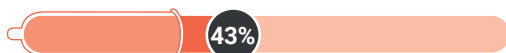
4 in 10 reported they were not sexually active



and were more likely to report feeling depressed or anxious

"I have a huge block on sexual relations, as previous experiences have made my head attribute this to something dangerous and gives me an uneasy feeling. Avoidance is the only coping technique."
MARKUS, 41

Despite over 95% of people with HIV being on treatment and with an undetectable viral load, of the 60% of people with HIV who reported being sexually active, 43% said that they used condoms during sex all of the time, even in monogamous relationships.



Proportion of people with HIV who were sexually active, with an undetectable viral load and using condoms during sex all of the time

10. The People Living With HIV Stigma Survey UK (2015), *HIV in the UK: Changes and Challenges; Actions and Answers, The People Living With HIV Stigma Survey UK 2015 National findings*.

The U=U message has helped to challenge internalised feelings of stigma and is reassuring for those who are unable to negotiate condom use. It has empowered us to embark on healthy and fulfilling sexual relationships. There is clearly real value in ensuring that everyone has access to information about U=U. However, not all people living with HIV know about U=U or the evidence behind U=U and therefore are unable to fully understand and trust U=U. It is vital that healthcare and support teams – especially clinicians – are clear and straightforward in their advice that HIV is not passed on through condomless sex when a person has an undetectable viral load.



For me and relationships, HIV has dominated everything. It is only now that the U=U message is really getting out there that I feel a weight getting lifted off my shoulders. So U=U is really important.” ROSS, 48

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.
- All people living with HIV should have access to specialised and high quality sexual and reproductive services, including support and information around starting a family and family planning, conception support for gay men with HIV, specialised peer support during pregnancy (mentor mothers), and support for women going through the menopause.
- Women-focused support must be offered to women living with HIV. These support services should be attuned to cultural and gender dynamics if women are to be empowered to access the information, support and networks they need in order to achieve good health and well-being.
- The women’s sector and the domestic violence sector (including those working with LGBT communities) must be protected and strengthened so that they can support people from diverse backgrounds and understand specific issues around HIV and intimate partner violence. GPs and HIV specialist services should have referral pathways in place.

- HIV specialist support should be retained locally both to meet needs that generic services are unable to provide appropriately (for example peer support), and also to complement, train and work alongside this generic provision.
- The government and local authorities must ensure targeted HIV information campaigns in communities affected by HIV, such as black African communities and among gay and bisexual men, include information on U=U.
- Clinicians working in HIV and sexual health must ensure that the U=U message is consistently communicated so that more people living with HIV and their sexual partners can make informed decisions about their sexual health.



A lot of people are still afraid of people with HIV. It's very difficult to date and tell everyone freely about my status as there is still a lot of stigma attached to having HIV." STELLA, 49



RELATIONSHIPS WITH HEALTHCARE PROFESSIONALS

Many people living with HIV rated their health as good or very good (73%). But, around three quarters of people living with HIV reported living with at least one other long-term condition. With the population of people living with HIV getting older, this proportion will only increase and for many of us, HIV will be less and less our primary health concern.



72% of people with HIV reported living with at least one other long-term condition

The HIV clinic has traditionally been involved in the broader care of people living with HIV. But, as the management of HIV becomes much the same as for other long-term conditions, the NHS priority to deliver integrated and person-centred care, including promoting self-care, is key. In this context, GPs rather than HIV clinics will have a central role in delivering care to people with HIV.

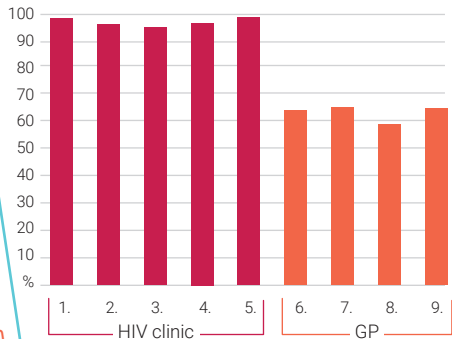
The survey asked participants to rate their HIV clinic and GP out of 10, and agree or disagree with the statements below.

HIV specialist services

1. "I have enough information about my HIV"
2. "I feel supported to self-manage my HIV"
3. "I am involved in decisions about my HIV care"
4. "At appointments, I have enough time to cover everything I want to discuss"
5. "The staff listen carefully to what I have to say"

General practitioner (GP)

6. "My GP knows enough about my HIV condition and treatment"
7. "I am comfortable asking my GP questions about my HIV"
8. "My GP is as involved as I want them to be with my HIV care"
9. "I feel that my HIV specialist and my GP communicate well regarding my health" (for those registered and disclosed to GP).



Survey statements

Average agreements* to statements

* Agreement was defined as a "Strongly Agree" or "Agree" response.

People living with HIV reported a high level of satisfaction with HIV specialist services. Average agreement to all statements about HIV clinic experiences was more than 95%, with small differences seen between groups. People agreed that their HIV clinics provided adequate information about their HIV and helped them self-manage their condition.

In contrast, agreement to all GP statements was lower at 59–65%. Overall, only 64% of people agreed that their GP knows enough about their HIV condition and treatment. Even fewer (59%) were comfortable asking their GP questions about their HIV. GP satisfaction among the general public closely mirrors GP satisfaction ratings of people living with HIV.

“ I have been under cancer treatment for five years and the oncologist that I am under has done a tremendous job of accepting the HIV and has treated me in an appropriate and thorough manner. Information is relayed back to my GP and my HIV clinician. But there is no communication whatsoever between my GP and HIV clinician.” JOHNNY, 61

Outside of the HIV clinic, healthcare providers may lack the knowledge or confidence to treat and prescribe for conditions where HIV is also present. This can leave us feeling responsible for educating non-HIV specialists about basic HIV facts, and researching drug interactions and treatment side effects. Mutual trust and open communication helps build good relationships with clinicians and GPs, as does becoming an expert patient. It can also give us the confidence to challenge instances when we are treated differently by someone in a healthcare setting.

“ If you live in a village where you do not have the luxury of having a choice of doctors, you have to get on with this GP. You can't make enemies. You need to maintain a healthy relationship with your local practice.” VINNIE, 52

Having our needs met relies on us being proactive and persistent in seeking support or advice. But not everyone is empowered to self-advocate for the treatment and care they need. Support from HIV services and peers can help us to gain knowledge, develop skills and form good relationships with our healthcare team.

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.
- The HIV clinic is only one part of a person's care, and models of care must be responsive to the changing needs of an ageing population of people living with HIV.
- 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.
- Clinicians and other service providers across the system should know about drug interactions and how to avoid them.
- The findings from Positive Voices should be considered in needs assessment and planning of future health and social care services for people living with HIV.
- Care must place us at the centre and be provided across a well-integrated system that we are confident in using.
- New models of care must consider the roles of the GP, social care, support services – including peer support – and other health specialists.





The stigma attached to HIV needs to change, as people are still incredibly naive about it. I certainly haven't told all my friends because I fear their reaction and judgement towards me. This doesn't bother me because I don't think they have to know as I am still the same person." **KELLY, 31**

Find out more

Visit 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

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

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

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