



Changing Perceptions

Talking about HIV
and our needs

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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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 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 for many people living with 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. Recent changes to the delivery of health and social care have been mainly driven by political and financial pressures, rather than evidence that provides a clear understanding of the changing needs of people with 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.



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

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.

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 UNMET NEED?

The Positive Voices survey asked people whether they used specific services (29 in total) in the past year, and whether they received that service. The services were split into three categories: HIV-related services (6), health-related services (11), and social and welfare services (12). People who had a specific need for which they could **not** get help or felt **not able to ask** for help were said to have an **unmet** need.



Our stories

LEARNING THE VALUE OF MY OWN LIFE THROUGH MY HIV DIAGNOSIS

Nicholas, aged 40, London

 HIV saved my life. Had it not been for HIV, I would have completely disconnected from society and I would have died on the path I was on. The only thing that kept me alive was coming back to the clinic to get my next round of HIV drugs. The HIV clinic I was able to refer me to other services for other conditions. This was the only thing that kept me going at some points and that taught me to value my own life for once.

I've been on a destructive journey. I used party drugs and once I got diagnosed with HIV, my drug use went from recreational to full blown addiction, including injecting crystal meth. I have been in drug treatment twice, have relapsed three times and have contracted hepatitis C twice. I knew I was having problems with addiction, and I remember going to my GP and getting a referral to mental health services. I saw a social worker, a psychologist and a psychiatrist all in succession, and at the end, they said "Oh this patient has so much insight. We will give him some leaflets and discharge him"...a year later I was diagnosed with HIV.

I have had a lot of battles accessing treatment. Without my HIV doctor, I wouldn't have had access to other types of secondary and tertiary care for a range of conditions from hepatitis C to tinnitus to skin cancer. My HIV clinic has been the hub for all of this, not my GP practice, where I found it was challenging to access a lot of care I needed. I know my HIV doctor went well beyond her call of duty to get social services to actually put me into residential rehab to treat my addiction when I thought suicide was the only answer.

My mental health is still an uphill battle. Now that I have stopped using drugs entirely, the underlying mental health issues that were there all along are now bubbling to the surface. The fact that my mental health needs are not being met means I am unable to get back to work and fully participate in society. I have felt as if I am in a sort of holding pattern.

Dealing with access to welfare benefits was probably the worst experience of my life. I was in residential care at the time, due to my addiction. At first my application was rejected so I had to appeal and go to tribunal with a voluntary barrister. The other conditions I was managing at the time had not been

properly considered. There is a relationship between pain, discomfort and all the other unmet needs I have as well as being a person living with HIV. I know a lot of people who are so dismayed by the benefits system that they give up and choose to suffer hardship. For me, quality of life means managing fear. Most of my fears centre on financial security because I am living on benefits from a hostile system.

HIV became this sinister character in my life that I battled with. In the beginning, I knew about and experienced stigma, but I also stigmatised myself. HIV had a grip on how I cared for myself and for my own self-esteem. However, today, I have accepted my HIV as part of me, been mostly drug-free for over two and a half years and feel resilient enough to tell my story.”

POSITIVE VOICES INSIGHTS

- Mental health problems were reported by half of people living with HIV, twice the rate of the general public.
- The relationship between mental health and drug use is well established and 23% of people with HIV reported recent use of recreational drugs (compared to 9% in the general public¹), rising to 40% in gay and bisexual men with HIV. This suggests a significant need for drug and alcohol services in people with HIV.
- Navigating the benefits system can be difficult when dealing with addiction and mental illness. Overall, about 1 in 3 (37%) of people with HIV in 2017 lived in poverty and a similar proportion currently claim benefits based on low income or disability. Services that provide help with claiming benefits, financial and employment advice, housing support and meal and food services remain important for people with HIV.



1 in 3 people with HIV live in poverty

“ I find it hard to ask for any form of help as communication can be difficult for me because of my mental health.” BRIAN, 52

1. Home Office (2018), *Drug Misuse: Findings from the 2017/18 Crime Survey for England and Wales*.

NO MORE SUFFERING IN SILENCE

Angela, aged 54, Birmingham



I grew up in a patriarchal society and married into one. My husband abused me for years with impunity. My fleeing to the UK was a way of getting distance from that life.

When I was diagnosed HIV positive in 2002, it was as if the bottom had fallen out from under my feet. The anger and bitterness from the abuse in my marriage intensified. I asked myself, “Why me?” I hated myself, the world and all that was in it. I blamed myself for everything. I even attempted suicide because I could not see a way out.

Since nobody had listened to me when I spoke of the abuse, it was difficult for me to disclose my status to anyone especially my family. I suffered in silence for a long time.

With the help of my HIV consultant, the specialist nurse, and a welfare officer, I began to open up. I was later referred to therapy and I started volunteering with a sexual health charity. Volunteering provided me access to group support, training and information about HIV. I had workshops and group therapy sessions with other people living with HIV.

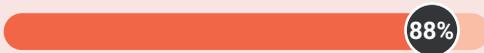
After a while, I disclosed my status to my sister, but her reception was very negative. She thought that just by volunteering for a sexual health charity I was bringing shame to our family. No one wanted to associate with me. I was excluded from family gatherings. The only place I felt I belonged was when I was volunteering or at the clinic.

Once my therapy progressed and I came to terms that nothing was my fault, I called my son who was in university at that time. When I told him my HIV positive status, he hugged me with tears rolling down his cheeks and told me whatever the status, I was still his mum and he still loved me. When my son got married, his wife accepted me as I am. Their love and acceptance has helped me overcome my depression and concerns with stigma.”

- HIV support services, often provided by charities or voluntary organisations, are a lifeline to many people with HIV. They provide specialist support and advice and connect people living with HIV to share experiences and build resilience.
- Two out of every 5 (44%) women with HIV had used such services at some point after their diagnosis, and the vast majority (88%) said this support had been important for their health and well-being.



Proportion of women with HIV who had used HIV support services



Proportion of women with HIV who found these services important

- However, of the estimated 10,000 women who needed peer support in 2017, nearly half (45%) did not get it.
- Furthermore, 3 out of every 10 women who currently use HIV support services said they found them more difficult to access in the past 2 years.



3 out of 10 women using HIV support services found them harder to access over the past two years



45% of women with HIV who needed peer support did not receive it

“Depression and isolation is difficult to cope with and the facilities and social spaces available to HIV+ people are becoming more and more difficult to access. Funding is constantly being reduced for mental health and well-being. HIV-related stress is inevitable.” CLAIRE, 61

OVERCOMING ISOLATION WITH A LITTLE HELP FROM MY PEERS

Ben, aged 65, North Yorkshire

 When I was first diagnosed with HIV in 2000, I was pretty ill and quickly ended up in intensive care for a few days, then in an isolation ward. I was divorced, with no partner, and my parents were both dead. I had young teenage children but I decided not to tell them about my diagnosis and burden them with fears of HIV.

In those first days and weeks I felt very alone. I was so ashamed and angry with myself...how could I have let this happen? Contracting HIV made me feel stupid, and dirty and ashamed. It was not something I wanted to tell other people about. But on the other hand, I really wanted to get a sense of what this all meant and what the future might hold. Although the doctors and nurses were great, they were busy and more concerned with my physical wellbeing, not my emotional state.

I was very pleased when someone from North Yorkshire AIDS Action (NYAA) came to visit. Caroline was very down-to-earth, and although not HIV positive herself, she had worked in the sector long enough to know the sort of things that were troubling me. It helped knowing there were others like me in North Yorkshire and that a safe space existed where we could meet and talk with one another. I was put in touch with a 'buddy' of a similar age who was also positive.

The peer support through NYAA sounded good to me at first, but the safe space was a 45 minute drive away and my buddy was even further away – a two-hour drive! Although it was helpful, nothing about it could be spontaneous; everything had to be planned in advance. Still, it was better than nothing, and in those early days, very comforting and helpful until I got some of my confidence back.”

- Loneliness and social isolation is a recognised public health issue that can have serious consequences on our health and quality of life. One in 5 people living with HIV said that they needed help dealing with isolation and loneliness in the last year, of which 75% reported that this need was unmet. This equates to over 13,000 people with HIV in England and Wales who felt lonely or isolated and were unable to get support in 2017.
- Isolation is a particular concern for people who live in rural areas where HIV prevalence is low and local support services are sparse. This makes it more difficult for us to meet other people living with HIV and to receive support with issues such as disclosure and HIV-related stigma.
- Over 10,000 people with HIV live in areas of low HIV prevalence, and are less likely to have ever used HIV support services. Over half (55%) of people living in rural areas reported unmet need for peer support or social contact with other people with HIV.



1 in 5 needed help dealing with isolation and loneliness



75% reported an unmet need for help dealing with isolation and loneliness



Unmet need for HIV support services in rural areas

LOOKING OUT FOR MYSELF WHEN MANAGING HIV WITH OTHER LONG-TERM CONDITIONS

Johannes, aged 49, Kent



I am originally from South Africa but in 2010, I moved to England to be with my civil partner and we now live in Kent.

My journey with HIV has been relatively easy in comparison to many people I've met, but I still have unmet needs. Some people think that because people living with HIV are on treatment, we are okay and are not worth worrying about. Quite often, healthcare workers tell me "you have no worries as you are on medication". But it's not that simple.

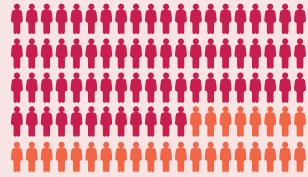
Recently, I have been struggling with angina and was very ill in 2017. I was treated by two doctors and two specialists who all had different opinions and were continuously changing my medications, and my health worsened as a result. It was primarily up to me and my HIV clinic to intervene and advise the specialists on what medications I should take. The Sexual Health Clinic at Canterbury was there from the start and their invaluable service helped to get my health back on track.

I worry about managing my other health conditions and how they interact with my HIV. Some NHS staff would rather print off information instead of having a meaningful conversation with me about HIV. It seems there is still a lack of understanding and knowledge about HIV, which makes it difficult for NHS staff to talk to their patients about it. If the patient and the sexual health clinic fail to be pro-active, a life is at risk.

I've been suffering with slow healing infections since my diagnosis, despite adhering to my HIV treatment. It is still a battle especially with dental issues and gum disease. My dentist often appears confused by my complaints. I think sometimes doctors and dentists alike forget everyone has a different biological healing clock. I have learnt to be patient and take recovery day by day.

No one is sure how HIV and other health conditions will be affected by ageing as I am part of this guinea pig cohort of people who acquired HIV in the early years of the epidemic, are now on ARVs, virally suppressed and managing other health conditions alongside HIV."

- Due to effective HIV treatment, we are living longer and with this our health and support needs are changing. Three out of every 4 (72%) people living with HIV had at least one other diagnosed long-term health condition. This equates to over 60,000 people managing HIV plus another long-term condition every day.
- Services must adapt to respond to the complex health issues facing people with HIV into the future – 42% of people with HIV said they needed advice on how to manage their long-term health conditions, and a third (33%) reported that this need was unmet.
- Nearly all (98%) respondents were on HIV treatment, and a third (38%) are also taking another prescribed non-HIV medication. Two-thirds (62%) said they needed HIV treatment advice.



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



42% of people with HIV needed advice to manage long-term conditions



People with HIV on HIV treatment



People with HIV also taking a prescribed non-HIV medication



People with HIV with a need for HIV treatment advice

- Many of the needs around HIV appear to be met, but managing multiple conditions and medications can lead to anxiety if the right support and information is not available. Work remains to educate GPs and other healthcare providers about side effects and drug interactions.

Met and unmet needs of people living with HIV

A common theme running through these stories is that the needs of people living with HIV are complex, change over time and go beyond the day-to-day management of HIV. When these needs are unmet it is often due to obstacles in accessing services, difficulty navigating health and benefit systems or lack of awareness that a service even exists.

The Positive Voices survey revealed significant levels of unmet need among people living with HIV in England and Wales, particularly for social care, support services and certain health services.

However, survey responses also painted a positive picture. In the past year, 4 in 5 people needed an HIV-related service, such as HIV treatment advice, adherence support, or peer support. In 80% of cases, respondents said that these needs had been met. This suggests that the majority of people with HIV can find the information and support they need from HIV clinics, HIV charities and voluntary organisations, or other places such as the internet.

The survey found extremely high levels of satisfaction with HIV clinical services, with participants rating their HIV clinic on average 9.3 out of 10. Over 95% of people reported feeling involved in decisions about their HIV care and enabled to self-manage their HIV.

“ I am a gay man who has lived with HIV for almost 20 years now. I have struggled and suffered with depression in the past, but have been fortunate in having fantastic support from my HIV clinic.” ANDREW, 56

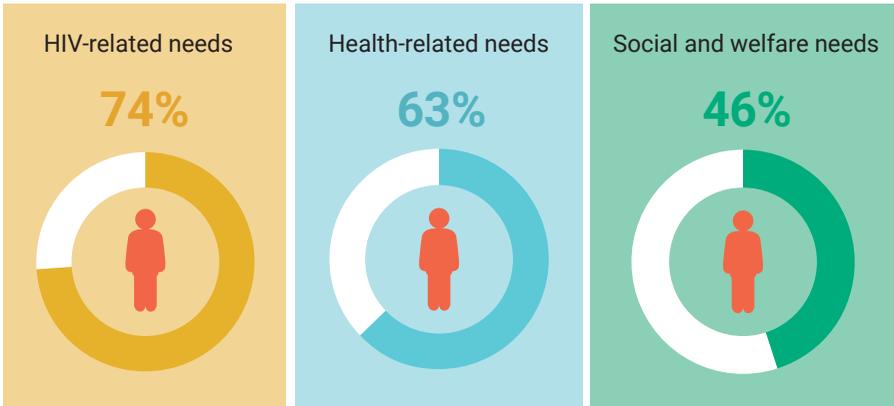


HIV clinics scored an average rating of 9.3 out of 10 for patient satisfaction

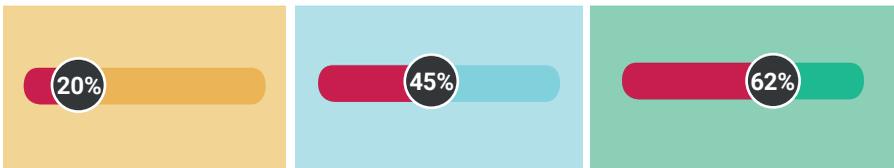
“ I am happy with the clinic I attend at the moment. The doctors and all nurses are friendly and they make life easy and bearable for people living with HIV and am grateful to have them.” FUNGAI, 31

In contrast, a similar proportion of respondents (77%) reported other health needs not related to HIV, and only half of people with other health needs had these met. Discouragingly, nearly half (46%) of people had a social and welfare need, and two-thirds (62%) of these needs were unmet.

Proportion of respondents with a need



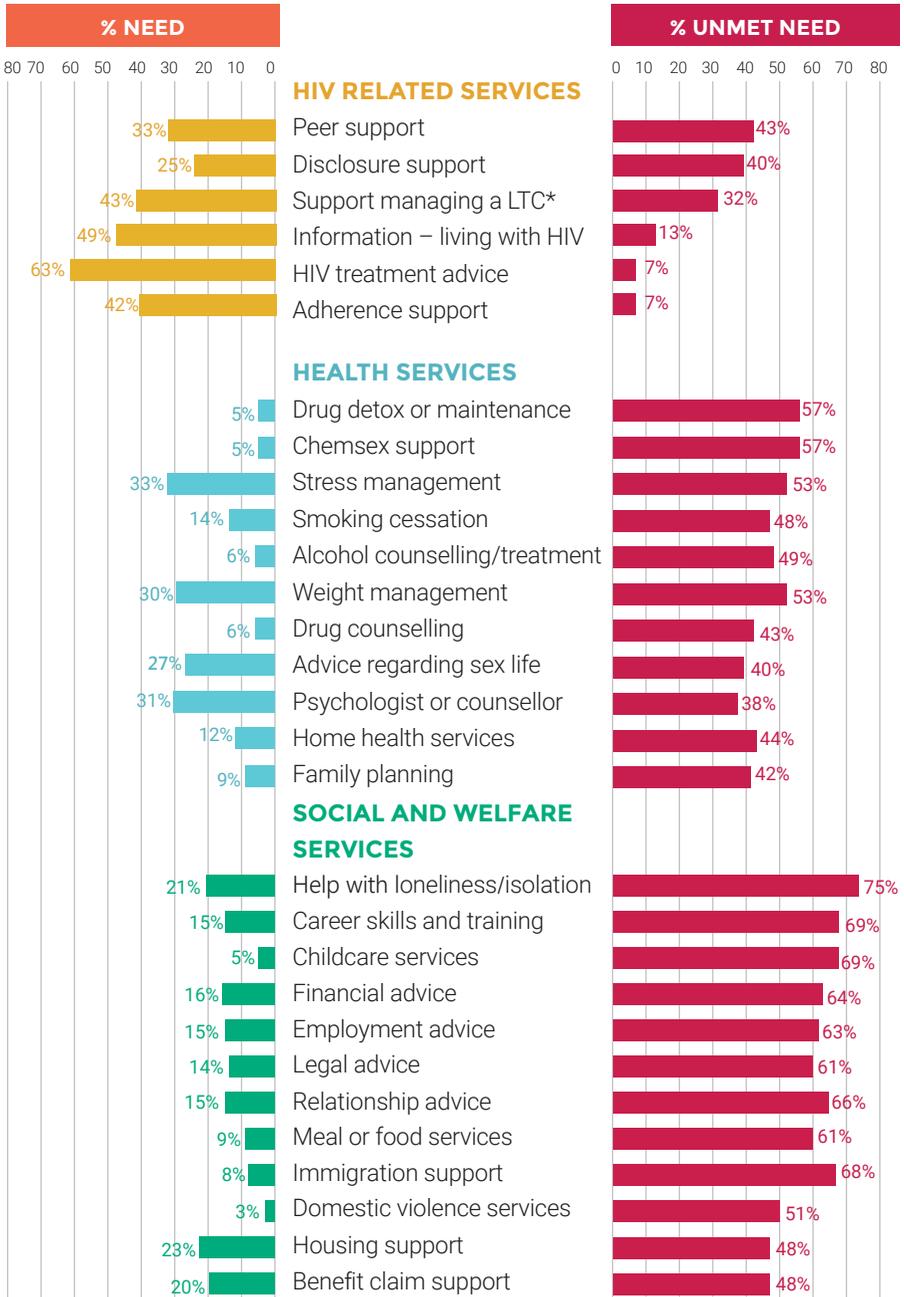
Proportion of needs that were unmet



Each need represents a personal concern or crisis that can have many possible causes. Some needs may be resolved by a simple intervention, while some may require ongoing support and may never be fully resolved. However, the impact of an unmet need can have serious consequences on our emotional and physical well-being, and ability to cope with daily life. In this section, we explore some of the key themes around ‘need’ that emerged from the stories and data.

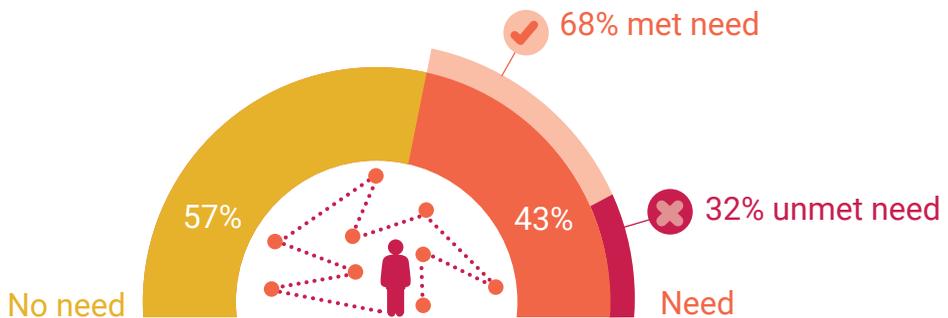
“ *The only people you can discuss your HIV condition with are staff at the HIV clinic. Nobody and no services exists to help you meet others with same condition. As an older patient the sense of isolation is higher.”* **CARL, 63**

Percentages of need and unmet need for services



* Long-term condition

LONG-TERM CONDITION SUPPORT



Help managing long-term conditions

Managing multiple health conditions is very common among people living with HIV and was reported by 73% of respondents. Conditions such as high cholesterol, hypertension and diabetes were all prevalent (affecting 29%, 23% and 7% of people with HIV respectively) and are known precursors of cardiovascular disease, for which people with HIV have double the risk.² Other common conditions reported included arthritis (12%), peripheral neuropathy (8%) and kidney disease (5%).

The survey also found that long-term conditions cluster (having one condition makes it more likely to get another) and increase with older age. With effective treatment, the HIV population is ageing and by 2023 over half of people with HIV will be over 50. Therefore, it is increasingly important that people with HIV have the information and advice needed to manage HIV and other health conditions and understand the possible effects of living with multiple health conditions.

The HIV clinic is the gateway for many to access services. However, this often depends on us being proactive and persistent in seeking support or advice and not all of us are able to self-advocate for the referrals we need.

HIV care and treatment *and* the management of non-HIV related conditions were historically provided by specialist HIV services until changes in the provision of care meant responsibility was split across the health system. This has resulted in a complicated care pathway that does not always meet the needs of people living with HIV.

2. Shah A.S.V., Stetlze D., Lee K.K., Alam S., Clifford S., Longnecker T.C., et al. 'Global Burden of Atherosclerotic Cardiovascular Disease in People Living with the Human Immunodeficiency Virus: A Systematic Review and Meta-Analysis'. *Circulation*. 2018 Jul 2.

Outside of the HIV clinic, healthcare providers can lack the knowledge or confidence to treat and prescribe for conditions where HIV is also present. This leaves many people with HIV feeling responsible for educating their GPs about basic HIV facts, having to research drug interactions and treatment side-effects, or possibly avoiding seeking healthcare.

“ I have often felt very low, maybe depressed, the GP guides me to a self-help website, the HIV clinic refers me to my GP. I would prefer all my healthcare issues to be addressed at the HIV clinic, as it is frustrating to be told by one to see the other as ‘it’s not their area of expertise’, and it is very difficult to get an appointment with my GP.” IAN, 60



One in 10 people living with HIV avoided care due to fear of stigma



“ I believe GP staff need more HIV-related education to be more informed, so that people like me are not put in a position where you would rather die of pain than go to the GP when there’s a need.” LETHABO, 39

14% of people with HIV experienced discrimination in the NHS last year

Robust communication and referral pathways are vital to ensuring that our clinical needs beyond HIV are met. Good communication between HIV clinicians and other NHS providers can be reassuring. If clinicians in other specialities know where to get up-to-date advice on HIV and drug interactions it will support better care.

“ There is lack of communication [between] my GP and clinic. My GP does not know my HIV tablets side effects and my HIV clinic does not want to know about my other health problems. This causes confusion about my medication. I need to be treated as whole wherever I go for treatment.” NOMSA, 60



My previous GP didn't even know that an HIV+ woman with an undetectable viral load can get pregnant and not pass the virus to the baby." CLARE, 48

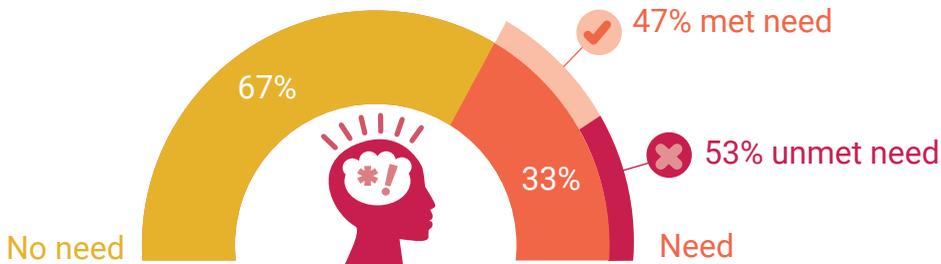
WHAT NEEDS TO BE DONE?

- 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.
- 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.
- The HIV clinic is only one part of our care, and models of care must be responsive to the changing needs of an ageing population of people living with HIV.
- New models of care must consider the roles of the GP, social care, support services – including peer support – and other health specialists.
- Care must place us at the centre and be provided across a well-integrated system that we are confident in using.
- People living with HIV should be regularly offered screening for preventable conditions such as cardiovascular disease and diabetes, in line with national guidelines on clinical management of HIV.
- Clinicians and other service providers across the system should know about drug interactions and how to avoid them.



Since the government changed the policy on the kind of care the HIV clinic can give, the level and quality of service has been poor and quite unreliable. You can't get all the treatment and address the concerns you have in the [HIV] clinic. You are referred to your GP who often doesn't know a lot." PRECIOUS, 42

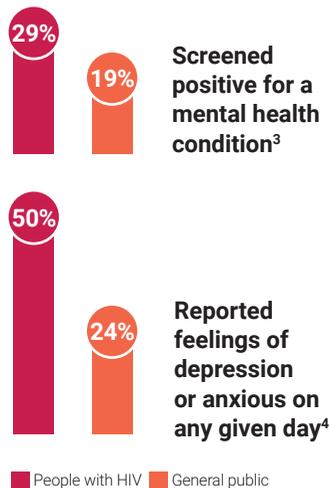
MENTAL HEALTH SUPPORT



Help managing stress

People living with HIV are around twice as likely to have mental health problems compared to the general public, depending on how it is measured.

The most common mental health conditions reported were depression (diagnosed in a third) and anxiety (diagnosed in a quarter). There was also significant experience of rarer conditions such as sleep disorders (15%), post-traumatic stress disorder (5%), psychosis/schizophrenia (2.4%) and bipolar disorder (1.7%). Significantly, the presence of mental health difficulties was the same across all ages, genders and ethnicities.



About 1 in 3 (31%) needed a psychologist or counsellor in the past year, but for 38% this need went unmet

“ Accessing the clinical psychology support services at my HIV clinic was fundamental to me coping with the loss of my relationship when first diagnosed with HIV.” BERNARD, 52

3. (Using GHQ-12 Score 4+). NHS Digital (2017), *Health Survey for England 2016 Well-being and mental health*.

4. (Using EuroQol). Devlin, N. J., et al. 'Quality of life: An EQ-5D-5L value set for England'. *Health Economics*. 2018; 27: 7–22.

Many of the needs identified in the Positive Voices survey are interrelated with mental health, for example loneliness and isolation, poverty, alcohol and drug use, and managing multiple health conditions. But many struggle to access the mental health services they need. This is exacerbated by the fact that some HIV specialist support services that would alleviate stress, promote well-being and prevent crises are becoming harder to access.

The link between HIV and poor mental health varies from person to person, but having HIV is clearly connected to how mental health is experienced. Most people in the survey (70%) had a mental health diagnosis around the same time or in the years following their HIV diagnosis. However, 30% had a pre-existing mental health condition diagnosed prior to HIV.

HIV can be a catalyst for negative feelings. In the 2015 UK HIV Stigma Survey 1 in 5 people reported having felt suicidal and more than half had felt shame, guilt or self-blame in relation to their HIV status in the past year.⁵

 *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*

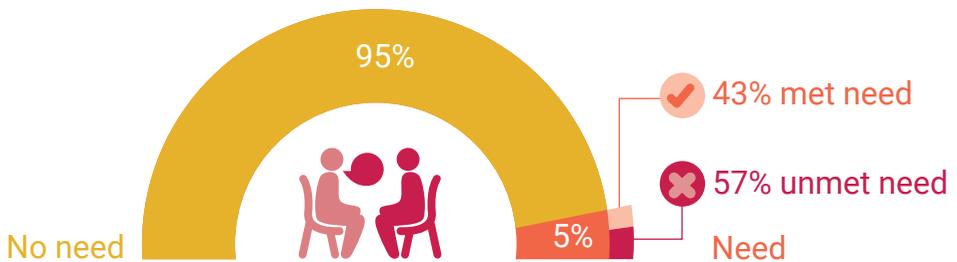
The HIV clinic was identified as important for signposting to mental health services. It is a place where people feel protected from stigma and this plays a role in supporting people to access the broader mental health support they need.

WHAT NEEDS TO BE DONE?

- Mental health services must be equipped with knowledge about HIV and create stronger links and referral pathways with HIV specialist services.
- People with HIV should be regularly offered mental health screening, with timely assessment and management by qualified mental healthcare professionals as needed.
- HIV commissioners should ensure that there is a clear pathway for mental healthcare for people living with HIV. This could include mental health services that are part of or connected to the HIV clinic, primary care services, and local mental health services.

5. 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.*

DRUG AND ALCOHOL COUNSELLING AND REHABILITATION



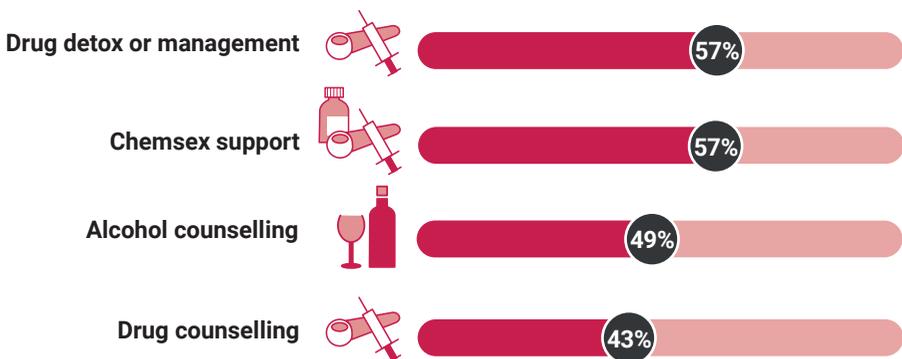
Help with chemsex support

Among people with HIV, binge drinking and use of illegal or non-prescribed drugs was commonly reported, particularly among gay and bisexual men – 41% reported binge drinking and 39% using drugs in the previous 3 months. In contrast, recreational drug use was reported by only 5% of women, although binge drinking was reported by 32%.

“ I am a recovering crack addict and opiates user. My low self-esteem and deep depression caused me to feel useless and suicidal.”
PASCAL, 49

Overall, one in 12 (8.5%) people with HIV reported a need for support around drug use – such as drug counselling, drug detox or maintenance and chemsex (sexualized drug use) support. Need for these services rose to 22% among people who reported recent drug use. 1 in 8 (12%) men and 1 in 25 (4%) women who binge drink said they needed alcohol counselling or treatment.

There were high levels of unmet need in these areas:



For many people, the unmet needs reflected an ongoing and potentially urgent issue: 70% of people who were not able to access drug-related support services continued using drugs.

“ *I have been waiting over six months for mental health services. It is believed that I have been suffering mental health issues since childhood. Methamphetamine is helping me control my day to day well-being and has been filling the void in the delay in accessing proper mental health services. My GP sees me as an addict and won't prescribe treatment. Tomorrow I see a psychiatrist.” LEE, 42*

When drug and alcohol support services are available, they can be highly effective at stopping a cycle of drug and alcohol abuse. These services offer strategies to overcome stress and anxiety, to improve self-confidence and create supportive social networks, and can help us to develop safer and healthier lifestyles.

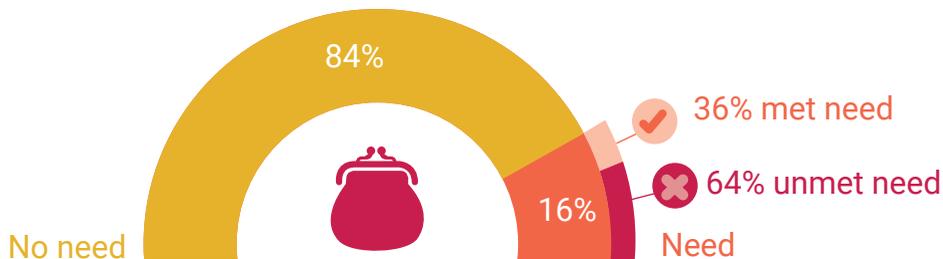
“ *I thought I could handle everything on my own but the reality of being positive takes a while to sink in and the impact it has on your social and sex life wears you down months after being diagnosed. It was then that I developed issues with drugs and alcohol. The counselling and support services I found were really helpful at that time when I felt completely alone and was struggling to cope.” SAJID, 32*

Drug and alcohol services are funded through local authorities as part of their public health remit and, while they have a duty to identify and meet local needs, there is no specific legal requirement to provide these services. The public health budget has faced significant cuts and clearly the services available are not adequately meeting the needs of people living with HIV.

WHAT NEEDS TO BE DONE?

- Drug and alcohol services must be properly resourced by increasing funding for the local authority public health grant.
- Drug and alcohol services should be equipped with knowledge about HIV and should build stronger links and referral pathways with HIV and sexual health specialist services.
- HIV commissioners should make sure that there is a clear pathway for support around drug and alcohol use for people living with HIV.

FINANCIAL SUPPORT AND ADVICE



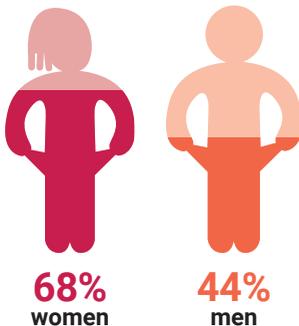
Help with financial advice

Financial instability affects many people living with HIV – 46% of women and 32% of men live at or below the poverty line (less than £20,000 annual household income). Access to welfare benefits is crucial for many people living with HIV to meet their costs of living – 56% of women and 30% of men with HIV are in receipt of some sort of means-tested benefit.⁶

One in eight (13%) people with HIV are in receipt of housing benefit, 13% get Employment and Support Allowance (ESA) or Incapacity Benefit, and 15% get Disability Living Allowance (DLA) or Personal Independence Payments (PIP).

Yet 68% of women and 44% of men said they do not always have enough money to meet their basic needs (e.g. utilities, food, rent), and 43% of women and 22% of men are behind with household bills. This is supported by the high unemployment rate for people with HIV – 2.5 times the UK average over the same time period in 2017 (11% vs. 4.5%).⁷

Not always having enough money to meet basic needs



Behind with household bills



6. DLA or PIP, Universal Credit, ESA or Incapacity Benefit, Jobseeker's Allowance (JSA), Income Support, Pension Credit, Tax Credits, Housing Benefit, National Asylum Support Service.

7. DWP aged 15-65, excluding economically inactive such as retired, students and carers.

Navigating the benefits system can create fear and anxiety. Many struggle to access the benefits they are entitled to, especially with the UK benefit system undergoing such big changes. A NAT review of the new PIP system raised significant concerns with how eligibility is assessed and how suitable the approach is for people living with HIV.⁸ The report found that the assessment criteria fail to consider issues relevant to people living with HIV, such as treatment adherence and the impact of living with a fluctuating condition.

The NAT review also found that the assessment process itself was a source of great stress. In the Positive Voices survey, 20% of people needed help in claiming benefits and 16% needed financial advice – but an alarming proportion of this need was not met. Nearly half (48%) of the need for help claiming benefits was unmet and two-thirds (64%) was unmet for financial advice.

Nicholas took his appeal to tribunal (see page 5). He is not alone. In 2016/17 almost 300,000 cases went through reconsideration by the Department of Work and Pensions (DWP) and 107,645 cases were appealed at tribunal.⁹ In 65% of tribunal cases, DWP's original decision was overturned; this only happened in 15% of DWP appeals of new claims (as opposed to reassessments).¹⁰ Not everyone is in a psychological or financial position to take this matter to court and HIV-related stigma may also act as a barrier to challenging decisions. High quality advice and support is therefore vital.

“ I was very lucky that my housing association provided a care support worker who helped me for a year sort out my PIP (went to tribunal). Before it was awarded, I couldn't pay bills, [and relied on] food banks.” ANGELA, 61

WHAT NEEDS TO BE DONE?

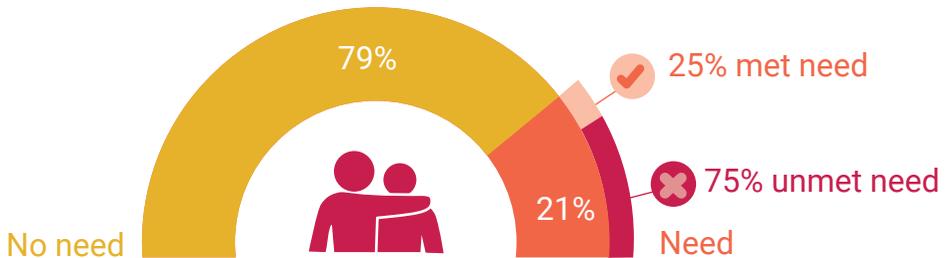
- The advice and support that people living with HIV need in order to access the financial support they are entitled to must be funded. These services are vital in preventing the negative impact that financial insecurity and claiming benefits can have on our health and wellbeing.
- Too many people are having to fight for the benefits they are entitled to. The system needs to learn and adapt. People living with HIV and other long-term conditions should be involved in assessing how well the benefits system works and ensuring that it is fit for purpose.

8. NAT (2017), *PIP and HIV*.

9. Ibid.

10. Ibid.

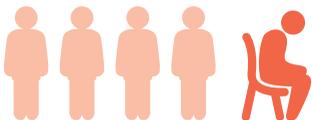
PEER SUPPORT AND CONTACT WITH OTHER PEOPLE WITH HIV



Help addressing loneliness and isolation

Supportive relationships, social networks and social interaction with other people who have HIV are all important for our well-being and quality of life. Talking about HIV and how it affects us can be pivotal to overcoming challenges.

But feelings of isolation and loneliness were commonly reported by 1 in 5 (20%) people with HIV. Of all the services examined, this had the greatest area of unmet need – 75% of people who needed help dealing with loneliness and isolation did not receive it. Feelings of loneliness and isolation were equally common across all ages, ethnicities, genders and areas of residence and similarly this need was mostly unmet for everyone.



1 in 5 people living with HIV reported feelings of isolation and loneliness

HIV support services can be life-saving for people with HIV, providing a wide range of services such as peer support, psychological support, sex and relationships support, information, advice and advocacy.¹¹ Of those who had ever used them, 81% said that HIV support services were moderately or very important to their health and wellbeing.

“HIV support services helped me positively in dealing with feelings of isolation. Gaining peer to peer support from others is immeasurable. Truly understanding that HIV is not a death sentence only came from meeting other survivors who have lived through the 80s. I only meet these people through support services.” WINSTON, 36

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

The British HIV Association's Standards of Care¹² recommend that everyone living with HIV should have access to peer support, but this is clearly not always the case. In 2017 an estimated 12,000 people living with HIV were not able to access peer support when needed, and a third (33%) of people who use HIV support services said they have been harder to access in the last two years.

These trends are predictable given the budget cuts to service provision. In England, local funding for HIV support services reduced by at least 28% from 2015/16 to 2016/17 (the actual figure is believed to be higher but is difficult to calculate from the data available).¹³

Some charities have scaled back services while others have closed altogether. People who live in rural areas or smaller towns and cities now have to travel further for HIV support, making it increasingly difficult to access.

“ *Peer support doesn't seem to be available where I live. There is little opportunity for support or social contact with other people with HIV. There seems to be lots in large cities but nothing in more rural areas.*” ALASTAIR, 62

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 that generic services are unable to provide appropriately (for example peer support), and also to complement, train and work alongside generic provision.

“ *Support services especially peer support, enabled me to understand my conditions and develop confidence and skills to manage HIV if I am not happy with services – support network helped with self-acceptance.*” MARIA, 50

12. British Psychological Society (BPS), British HIV Association (BHIVA) and Medical Foundation for AIDS & Sexual Health (MedFASH) (2011), *Standards for psychological support for adults living with HIV*.

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



HIV support services have helped me learn to love myself and have introduced me to some amazing people. Health wise, if it wasn't for a peer support member, I would have never known that one of the side effects which had drastically affected my life since I went on medication, were caused from one tablet, which when mentioned to my HIV consultant, resulted in a change of medication and a drastic improvement to my quality of life." JOHAN, 41

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