

# isolating

## States of Mind: Improving mental wellbeing in the HIV community

We want change. We are positive.



POSITIVELY UK

September 2013

Research and report publication  
sponsored by Janssen

janssen 

# Foreword: why we wrote this report

---

While the concept of being 'healthy' is often tied to physical condition, at Positively UK (Pos. UK) we believe our mental and social wellbeing goes hand in hand with our physical health. Many of us experience problems affecting our mental wellbeing at some time in our lives, though these problems may go unnoticed and unaddressed.

The links between mental wellbeing and HIV are well-established, however there are several factors preventing these problems from being addressed. People living with HIV (PLWHIV) may not feel confident enough to discuss their mental wellbeing, or be sufficiently informed about the support available. Furthermore, the essential HIV services providing support and care are not always able to reach those who need it most.

As a peer-led service provider, Pos. UK offers help and support for the physical, emotional and social wellbeing of PLWHIV, which includes mental health. Our frontline staff and volunteers have considerable experience of the challenges their peers face with their physical and emotional wellbeing as many of them are themselves living with HIV. However, to gain deeper insights and ensure our services support the mental wellbeing of the HIV community as effectively as possible, we conducted research to find out:

- How prevalent are mental health issues among PLWHIV?
- How does mental wellbeing impact adherence to antiretroviral treatment?
- How does discrimination experienced by PLWHIV impact their overall and mental wellbeing?
- How are support providers addressing the issues around mental wellbeing and could improvements be made?

In this report and in all our work, we aim to champion the rights of PLWHIV and increase involvement, voice and visibility to improve the support and information available for the HIV community. We hope that the insights in this report will empower and equip PLWHIV with up-to-date research that helps frame individual experiences. For support providers and healthcare professionals, we hope the report provides areas for further consideration on which to further improve the support available. Nobody should feel alone in managing their HIV and we hope that this research provides further support for PLWHIV throughout the country.



**Allan Anderson**, CEO, Positively UK



# How we did it

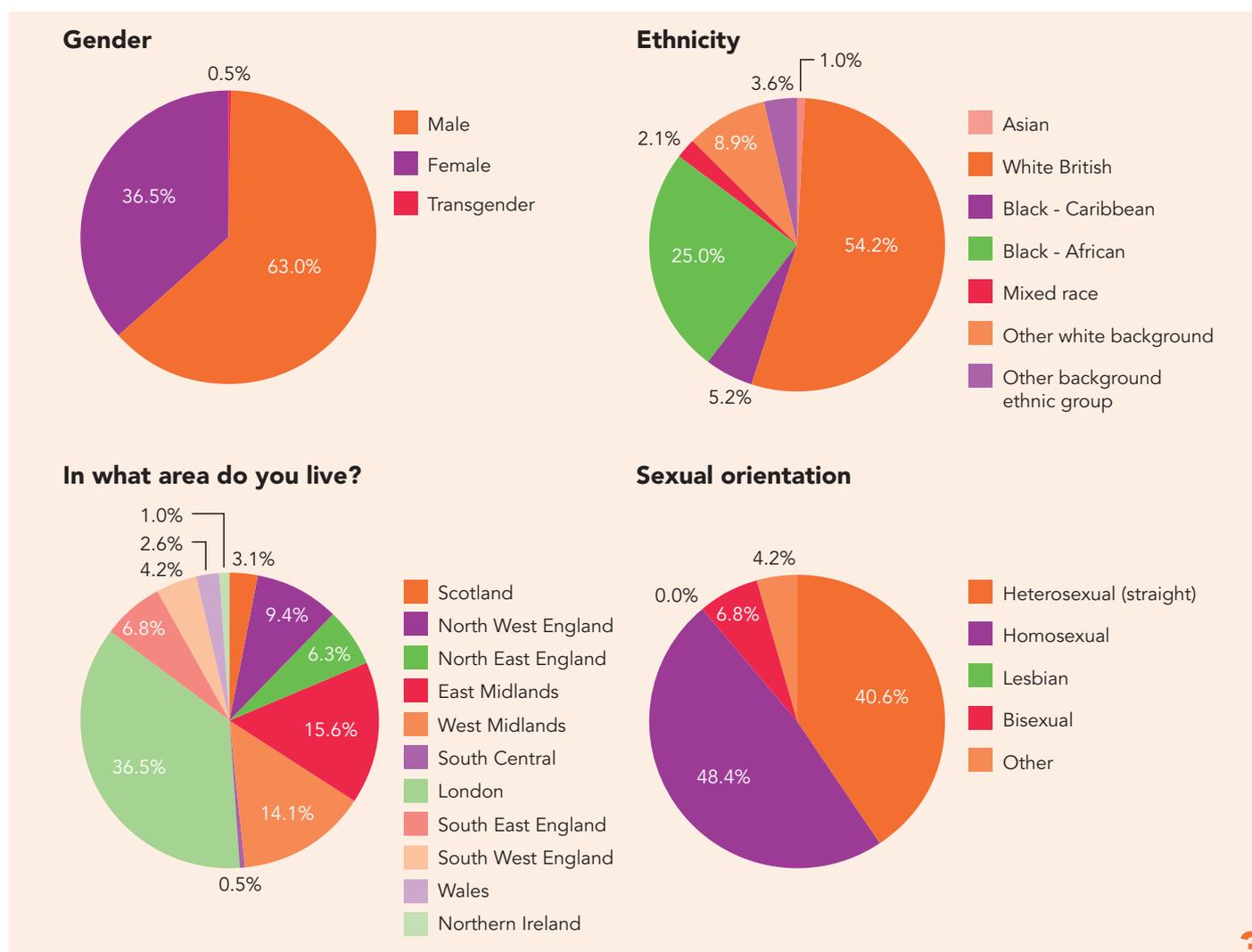
The research on which this report is based was conducted as an online survey and distributed to service users of Pos. UK and several other UK HIV community organisations throughout the UK. Participants were primarily recruited through each support agency via an email explaining the aims and objectives of the research. Participants were also recruited through advocacy group website articles and online at the [www.lifewithhiv.org.uk](http://www.lifewithhiv.org.uk) and UK-CAB HIV support networks. Recruitment also occurred in some groups through informal local meetings and through word of mouth.

While the majority of service users completed the survey online, service users of the Leicestershire AIDS Support Services (LASS) group were also offered the opportunity to complete paper copies of the survey. These surveys were then entered into the online survey by Pos. UK staff. The survey opened on Monday 8th April 2013 and closed on Monday 15th July 2013.

# Who we reached

In total, 192 people completed the survey, of whom 171 responded online and 21 via paper surveys.<sup>1</sup> As shown in the graphs below, the population surveyed broadly reflected the gender, sexuality and ethnicity of PLWHIV in the UK today.<sup>2</sup> Although it was not possible to achieve an entirely representative geographic split, 63% of survey respondents were based outside London which avoided a London bias.

- 63% surveyed were male (n=121), 36.5% female (n=70), and 0.5% transgender (n=1)
- 54% surveyed were white British (n=104), and 25% black African (n=48)
- 48% surveyed said they were homosexual (n=93), 41% heterosexual (n=78) and 11% bisexual/other (n=21)
- 37% surveyed were from London (n=70), 30% from the Midlands (n=57) and 9% from the North West (n=18)



# What we found

## Mental health issues continue to represent a significant burden for people living with HIV

It is well-established that PLWHIV are more likely to experience mental health problems than people living without the virus. The reasons for this are varied but include the complex and long-term nature of HIV infection, stress around diagnosis and the side effects of some anti-HIV medications.<sup>3</sup>

**“Whenever I remember that I have this disease I feel lonely and stressed”**

Our survey confirmed that the incidence of mental health issues among PLWHIV is common and outstrips other co-morbidities including high blood pressure, migraine and sexual dysfunction. These issues were found to be prevalent among those who received a diagnosis recently, as well as those diagnosed up to and over 20 years ago, suggesting that support may be needed regardless of the time of diagnosis, including for older people who have been living with HIV for several years. While the relatively limited sample size of the study does not allow for sufficiently detailed conclusions about this, further research on time of diagnosis and mental health may be valuable.

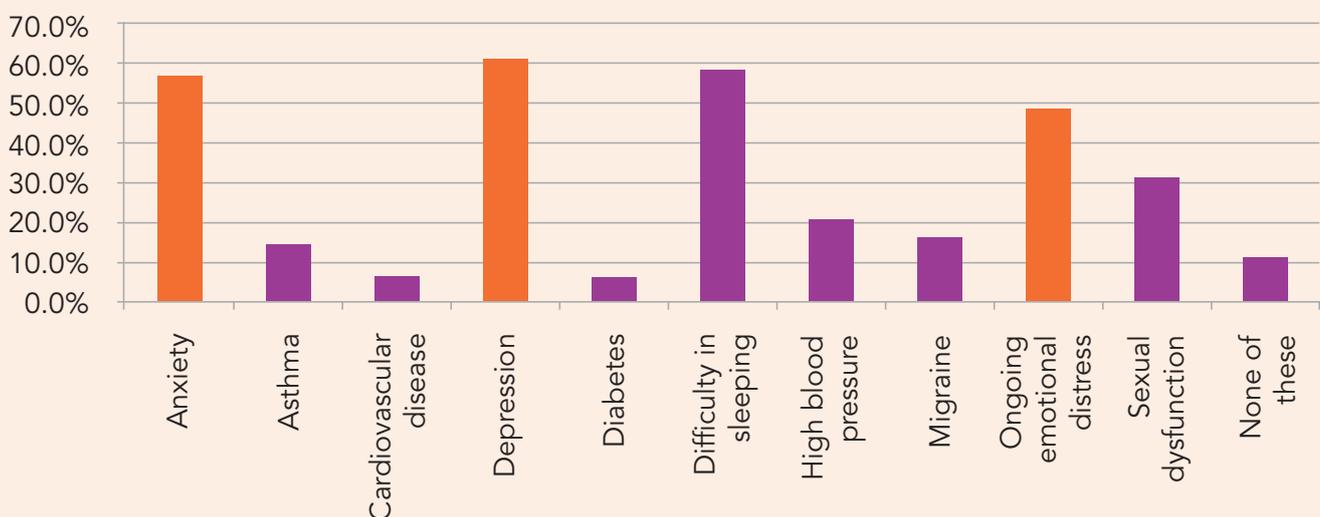
Three quarters of respondents (n=144) stated that they had suffered from either depression, anxiety or ongoing emotional distress in the past 12 months. Six out of ten respondents (n=115) stated that they had suffered from depression in the same period. Furthermore, when asked which condition has had the biggest impact on their quality of life, almost a third of respondents (31%, n=52) cited depression.

**“I have difficulty being motivated to take care of myself”**

Of those who had suffered depression (n=52), almost two thirds (62%, n=32) considered the condition to have had a ‘huge impact’ on their quality of life\*. The need to address the mental wellbeing and in particular depression among the HIV community is therefore pressing.

\*When asked the question ‘Overall how much of an impact has this condition had on your everyday life’ and provided with a scale of 1-10, 1 meaning little or no impact and 10 meaning a huge impact, these respondents answered between 8 and 10.

**In the past 12 months which of the following conditions have you suffered from?**



**“HIV is not just affecting me but my two little boys...  
I can't talk to them and explain what's really happening to  
my life and that takes me straight to depression all the time”**

### **Mental health and women**

Further analysis of respondents who had suffered depression, anxiety or ongoing emotional distress in the past 12 months suggested that mental health issues may be more prevalent among women with HIV. Seven out of ten female respondents (70%, n=49) fell into this category compared to almost half of men (48%, n=59).



### **Mental health and sexuality**

Gay men are considered to be more at risk of mental health issues due to the stresses associated with being marginalised from much of mainstream society.<sup>4</sup> Despite this, our survey suggested that the experience of mental health issues in the past 12 months applies in similar frequency to both homosexual and heterosexual PLWHIV. Of heterosexual respondents, 60% (n=47) stated that they had experienced depression, anxiety or ongoing emotional distress in the past year. This compared to 50% of homosexual respondents (n=47); while the incidence of the individual mental health issues was comparable across the two sample pools.



### **Mental health and communication**

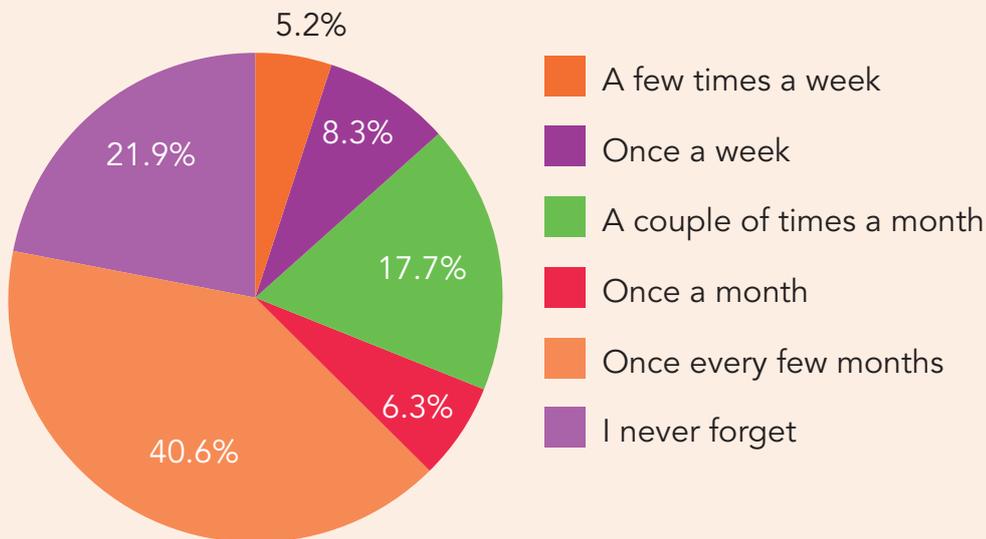
Encouragingly, four out of five people (80.6%, n=112) who had experienced mental health problems in the past 12 months had discussed the issue with their doctor or nurse. In contrast, when asked if they had discussed these issues with their support worker, almost half of respondents (48.6%, n=68) had not. In open-text responses, respondents provided a number of explanations for not discussing their mental wellbeing with support workers which included not wanting to burden others and not knowing how to approach the subject. In addition, many respondents stated that they did not have access to a support worker, meaning that they were unable to seek help of this nature.

## Adherence to treatment continues to present a challenge

Arguably the most significant burden of living with HIV is the need to take medication on a daily basis for life. Accepting that it is unrealistic to expect 100% adherence to be adopted universally among the HIV community, our survey explored the issue with a view to understanding why people fail to regularly take their treatments.

**"HIV causes me to be depressed and I neglect to take my medication"**

### Can you estimate how many times in the last 6 months you have forgotten to take your medication?



We found that only one in five respondents (21.9%, n=21) stated that they had never forgotten to take their medication in the past six months. When considering adherence on a daily basis and asked the question, 'Do you generally remember to take your medication each day?' three out of five respondents (63.8%, n=111) felt that they adhered to treatment. This increase may suggest that whilst PLWHIV feel they are adherent on a day-to-day basis, in the longer term the reality is that poor adherence is more common.

### Mental health and adherence

We found that almost a quarter of respondents (24%, n=23) to the question 'Why do you sometimes not take your anti-HIV treatments?' stated that they missed doses due to mental health problems that included depression. This compared with two thirds of responses (66.7%, n=64) stating that, "I just forget sometimes," – a statistic suggesting that a survey to further explore the real reasons for adherence would be a valuable piece of work for people providing treatment and support to those living with HIV.

**"I constantly forget but my partner reminds me"**

**24%** of respondents missed doses due to mental health problems

## Discrimination and stigma persist

It is important to distinguish between discrimination, where people treat others differently in a way that is unfair, and stigma, which typically is seen in people's attitudes or beliefs about others.<sup>5</sup> Free-text results from our survey suggest that confusion exists even among the HIV community with many respondents describing attitudes adopted towards them by peers, friends, colleagues and family as 'discrimination'. Definitions aside, the survey clearly showed that there is a way to go towards eradicating discrimination against PLWHIV and further education is needed.

**40%** of respondents experienced discrimination in the past 12 months

Discrimination against PLWHIV is a longstanding problem in the UK and our survey results suggested that this remains the case. Four out of ten respondents (40%, n=74) said that they had experienced discrimination due to their HIV positive status in the past 12 months. Descriptions of the types of discrimination experienced, provided in free-text responses were wide and varied. They included experiences within healthcare systems including dentists and within employment.

Further results from our survey revealed that colleagues and dentists were two of the groups that PLWHIV are least willing to disclose their positive status to. A quarter of respondents (24.9%, n=43) stated that they had not informed their dentist of their status. Almost four out of ten respondents (38%, n=57) preferred not to disclose their positive status to any of their colleagues.

**"I think about HIV 24/7. It upsets me and I cannot talk to my family, GP or friends about it"**

Furthermore, one in five respondents (19.9%, n=35) had not disclosed their HIV status to any of their family members and a further 40% (n=71) stated that they had only informed some family members.

**"When I talked to my husband about my status he started to treat me like a stranger in our marriage and turn all my family and friends against me. He locks me indoors with no people to talk to, he avoids my cooking and everything I ever touch"**

## Hospitals and HIV charities have a critical role to play in HIV

In evaluating our survey findings around mental health, adherence to treatment and discrimination, we considered the important role HIV services play in supporting people's wellbeing. In asking the question 'which services do you use in relation to your HIV positive status?' we sought to understand which types of support PLWHIV were actively using.

### Treatment centres

Unsurprisingly, more than 90% of respondents (93%, n=170) make use of a specialist hospital clinic in the treatment of their HIV. In contrast, 31% of respondents (n=49) do not make use of a GP practice demonstrating the specialised nature of HIV care and the importance of hospitals in both treating PLWHIV and educating them about the condition. The important role that hospitals play in treatment was supported by the fact that six out of ten respondents (61.1%, n=116) stated that they seek information from their doctor, nurse or pharmacist.

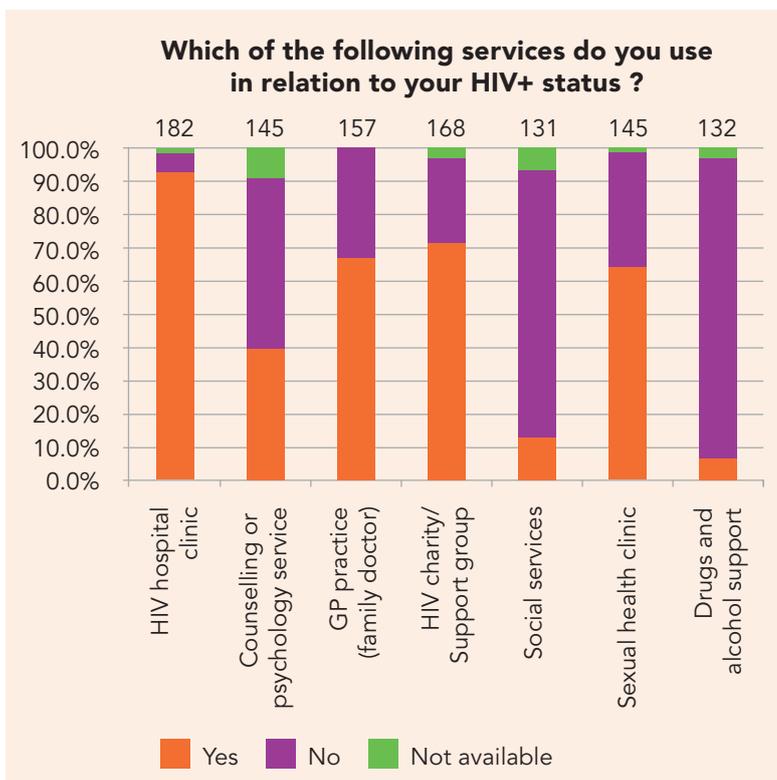
Four out of ten respondents (40%, n=58) make use of counselling or psychology services in the treatment of their HIV. In contrast, approximately half of respondents (51%, n=74) do not make use of these services and around one in ten respondents (9%, n=13) stated that these services were not available to them.

### HIV charities/support agencies

Seven out of ten respondents (71.4%, n=120) make use of HIV support agencies and six out of ten respondents (61.6%, n=116) stated that they seek information from these agencies. Whilst this finding is not surprising in light of the survey methodology, it still underlines the important role that HIV charities have to play in providing support to people.

### Information on the internet

The internet was the most popular source of information for survey respondents; two thirds of respondents (65.8%, n=125) stated that they get information about HIV and treatment online.



**"Clinicians and agencies need to work more holistically and refer more readily when issues arise in order to help people who are in distress"**

**"I just try to deal with it myself. I do not want to bother others"**

# What does it mean?

---

<b>Improvements must be made across all HIV services to tackle the ongoing challenge of mental health issues in the HIV community</b>	The findings of this report further reinforce the need for comprehensive support for PLWHIV who experience mental health problems, and most commonly, depression. Since the issue is not unique to any one group, service providers should maintain an open mind about who may require support and, wherever possible, work to prevent the occurrence of poor mental health in the first instance. The HIV community should be encouraged to seek support and likewise, service providers should take steps to ensure that the support available is well publicised and support staff are trained to ask relevant questions about mental health and emotional well being.
<b>Increased dialogue between PLWHIV and healthcare professionals is needed to better understand the complex relationship between mental health and adherence</b>	The relationship between mental health and adherence to treatment is a complex one. Improved, alternative approaches to communication between healthcare professionals and PLWHIV may provide deeper insight in this area. Healthcare professionals should consider different questions or discussing varied aspects of a patient's wellbeing when in consultation to broach the subject. Equally, PLWHIV may consider using the discussion points provided in this document to guide conversations with healthcare professionals and/or support workers.
<b>Closer coordination is needed between multidisciplinary support functions</b>	There is an opportunity for the wide range of advocacy groups and professional medical and social care bodies to consult more closely, for example through collaboration at annual meetings and other events. Closer coordination between healthcare professionals and these organisations, nationally and locally, on issues related to mental wellbeing will help ensure a more effective allocation of service provision, particularly to improve access to support workers and services in areas where it is limited.
<b>Tackling discrimination against PLWHIV has a role to play in improving the mental wellbeing of the HIV community</b>	The NHS should continue to lead the way in promoting the equal treatment of PLWHIV. Recent legal changes allowing healthcare professionals with HIV to perform procedures demonstrate the advances that continue to be made in tackling negative attitudes. Similarly, PLWHIV should be encouraged by support agencies to familiarise themselves with how to report discrimination, rather than stigma, to the appropriate bodies. With greater outreach and support for PLWHIV, discrimination can be overcome and, eventually, wiped out.
<b>The rights of PLWHIV to good mental health should be championed</b>	Mental health must remain high on the agenda for all those living with, and supporting those with HIV. While a relatively small study like this cannot demonstrate the complex connections between mental health, treatment adherence, discrimination, and service provision, the findings still provide valuable insights that reinforce the links between these issues.

Our overall wellbeing, regardless of HIV status, relies on individuals and service providers taking our mental health as seriously as our physical health, whether or not the signs and symptoms are obvious. PLWHIV deserve to feel well in mind and body, and we hope the insights in this report help to improve the quality of life for PLWHIV throughout the UK.

# Discussion points for PLWHIV

---

The checklist below has been developed to help you discuss the report findings and what they may mean for you with your support worker. While you may only want to cover some of these topics, it is important you feel able to discuss these issues and receive any additional support you may need.

<b>I have been feeling depressed and anxious and think it may be related to my HIV</b>	Have you felt, anxious, angry or depressed in the last month? HIV support providers may be able to provide information on whether your medicine is suitable for you, as some HIV drugs can have an impact on your mental wellbeing. They can also advise you on where you might be able to seek psychological support.
<b>I have been having some very troubling thoughts and do not know where to turn</b>	Your HIV support provider will be able to recommend external services, such as counselling or peer-led support, to help you deal with difficulties that may or may not be related to your HIV.
<b>I am having trouble sleeping and think it may be related to my HIV</b>	If you have experienced persistent problems sleeping, it may be because of the HIV drugs you are taking, or be a sign of stress, depression or anxiety that your HIV support provider will be able to help with.
<b>I am worried about privacy when taking my HIV drugs</b>	Do you feel able to take your medicine when in public or at social engagements? Are there any particular challenges to taking your medicine at home or at work? HIV support providers may be able to advise on how to take your treatment while maintaining your privacy, and can advise on approaches to disclosing your HIV to others.
<b>I am worried that I am not taking my HIV drugs correctly</b>	Do you sometimes forget to take your medicine or get confused about when to take it? Do you have problems swallowing pills? HIV support providers may be able to help you set reminders for taking your medicine or help you find a treatment that involves taking fewer or smaller pills.

---

## Acknowledgements

We would like to thank every individual who took the time to complete the survey, as well as the following support agencies that were instrumental in gaining these insights: AB Plus, African Health Policy Network, Body and Soul, Body Positive North West, George House Trust, GMFA, Herts Aid, Leicestershire AIDS Support (LASS), Lesbian and Gay Foundation, Mesmac, National AIDS Trust, Naz Project London, Positive East, River House, Sahir House, Staffordshire Buddies, Terrence Higgins Trust, Thames Valley Positive Support, UK-CAB, Waverley Care.

Positively UK has received support from Janssen to conduct the research. Janssen has a heritage of developing innovative HIV treatments and is committed to the future fight against HIV and providing information and support for people with HIV and those working with them.

Positively UK is a registered charity (Charity Number 1007685).

## References

The majority of statistics cited throughout this report come from the Positively UK mental wellbeing survey. All free-text comments from the survey are written as they appeared, though minor style and grammatical corrections were made in some places. Where other references are cited to provide further context, these are provided below.

1. Positively UK mental wellbeing in HIV survey. Data on file
2. Health Protection Agency. HIV in the United Kingdom: 2012 Report. Available from: [http://www.hpa.org.uk/webc/HPAwebFile/HPAweb\\_C/1317137200016](http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317137200016) [last accessed September 2013]
3. World Health Organization. HIV/AIDS and mental health: Report by the secretariat. 2008. 124: 4.3 Available from: [http://apps.who.int/gb/ebwha/pdf\\_files/EB124/B124\\_6-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/EB124/B124_6-en.pdf) [last accessed September 2013]
4. NAM aidsmap: Mental Health factsheet. Available from: <http://www.aidsmap.com/Mental-health/page/1044702/> [last accessed September 2013]
5. NAM aidsmap: HIV, stigma and discrimination factsheet. Available from: <http://www.aidsmap.com/stigma/What-is-discrimination/page/2260812/> [last accessed September 2013]

---

## Contact us

Whether you are newly diagnosed or have been living with HIV for years, Positively UK is here to support you. Our front-line staff and volunteers all have a firsthand understanding of the issues you may face as they are living with HIV themselves. To find out more about our services, access support, or just talk to someone else living with HIV, contact us via the information provided:

**Telephone:** 020 7713 0444

**Helpline:** 020 7713 0222

**Email:** [info@positivelyuk.org](mailto:info@positivelyuk.org)

**Registered Charity No.** 1007685



The prevalence of mental health problems in PLWHIV is higher than the general population. However PLWHIV may not receive adequate care as they may not seek support for these difficulties. Healthcare professionals may also not be trained to detect these problems or refer them for further assessment.<sup>1</sup> Our survey asked participants questions about the mental health conditions they experienced over the last year. The research found...

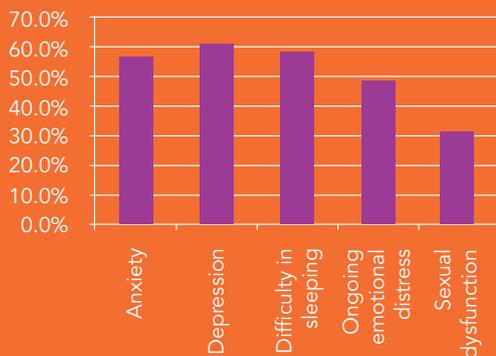
# 3/4

of PLWHIV have suffered from **depression, anxiety or ongoing emotional distress**



There is a gap between PLWHIV who experience mental health problems and those who seek help for them: **only 4 in 10 use counseling or psychology services**

In the past 12 months which of the following conditions have you suffered from? Please tick all that are applicable.



Depression is the most common mental health condition experienced, affecting **6 out of 10** people in the past year. Other conditions include anxiety, difficulty sleeping, ongoing emotional distress and sexual dysfunction.

# 7 out of 10 women

living with HIV experienced mental health issues in the past year, compared to 5 out of 10 men.

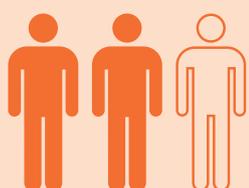
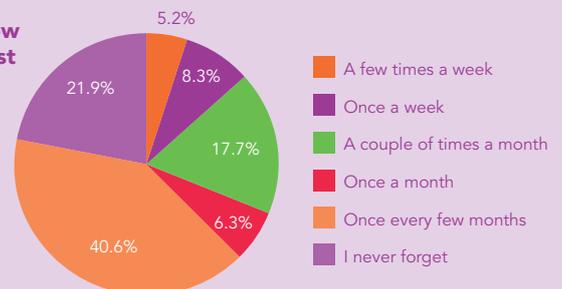
# 1 in 4 people

say they miss doses of antiretroviral medication due to mental health problems.



When asked how often they miss treatment doses, only **1 in 5 people** said they never forgot to take their medicine.

Can you estimate how many times in the last 6 months you have forgotten to take your medication?



## "just forget sometimes"

**2 in 3 people** say they "just forget sometimes", suggesting a need to further consider why they don't take their treatment.

**You Tube**



An interview with Positively UK with further information on the report is online at the **Janssen in HIV YouTube channel**