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October 2021



# HIV and mental health:

Improving generic NHS talking therapy  
services for people living with HIV in England

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# 1. Introduction

Awareness of mental health has increased significantly in recent years. Major campaigns have drawn attention to the importance of looking after our minds as well as our bodies. Historic stigma around mental health has begun to be challenged. The link between mental and physical health is widely recognised, especially in relation to long-term conditions.<sup>1</sup>

As the profile of mental health has grown it has started to be increasingly prioritised by Government and the NHS. Evidence of this can be seen in the NHS Long Term Plan's commitment to increase spending on mental health faster than the NHS spending overall, representing a significant increase in funding by 2023/24. After decades of underinvestment in mental health, this is a step in the right direction.

For many people with long-term health conditions, the ongoing challenges of managing a health condition can contribute to and be intertwined with challenges to mental health. People living with HIV are twice as likely to experience feelings of depression or anxiety than the general population, and more than 1 in 3 report being diagnosed with a mental health

condition at some time.<sup>2</sup> Despite major progress in treating and preventing HIV, HIV stigma remains rife, contributing to poor mental health, isolation and loneliness, and often preventing people from getting the help they need.<sup>3</sup>

Addressing the mental health needs of people living with HIV is vital to support people to live their lives to the full – to thrive rather than just survive. Good mental health is also shown to support adherence to HIV treatment, helping people to stay healthy and maintain an undetectable viral load (see section 1.1). This eliminates the risk of onward transmission of HIV. Effective mental health support for those with HIV, rather than being a 'nice to have', is vital if we are to reach the Government's aim of ending HIV transmission in England by 2030.

The importance of appropriate mental health support for people living with HIV has long been discussed and researched. However, the types of support available and the provision of that support are still not consistent across the country. This leaves people falling through cracks in the system or having to rely on generic mental health services. These services are known as IAPT (Improving Access to Psychological Therapies) – see section 1.2 for more information.



**For many people with long-term health conditions, the ongoing challenges of managing a health condition can contribute to and be intertwined with challenges to mental health.**

<sup>1</sup>Centre for Mental Health and National Voices, 2021, Ask me how I am: Supporting emotional health among people with long term conditions [<https://www.nationalvoices.org.uk/publications/our-publications/ask-how-i-am>]

<sup>2</sup>Public Health England, 2020, Positive Voices: The National Survey of People Living with HIV, Findings from the 2017 survey [<https://www.gov.uk/government/publications/hiv-positive-voices-survey>]

<sup>3</sup>APPG on HIV and AIDS, 2019, The Missing Link: HIV and mental health [<https://www.appghivaid.org.uk/s/The-Missing-Link-Web-version.pdf>]



## Good physical and mental health support are both essential for people living with HIV, for their wellbeing and long-term health outcomes.

The findings of this report demonstrate the limitations of relying on IAPT alone for people living with HIV and the need for improvements to services. While IAPT can work for some people living with HIV, issues such as a lack of HIV literacy and poor integration with wider HIV care hamper its effectiveness. This leads to unsatisfactory outcomes and poorer patient satisfaction.

It must also be recognised that there is a cohort of people living with HIV for whom IAPT services will never be suitable due to the complexity of their needs. IAPT should never be seen as a substitute for services that are designed to meet these needs, such as clinical psychology services within HIV clinics. Rather, we need a mixed economy approach for mental health services that acknowledges and meets the wide range of needs presented by people

living with HIV. Such an approach depends on the availability of appropriate services at every level of need. This report aims to ensure that IAPT services can play as effective a role as possible in this mixed economy of mental health support.

By drawing on the findings of our research and the expertise of our Advisory Group, we have developed a range of recommendations to improve IAPT services for people living with HIV. These recommendations will enable IAPT to better meet the needs of this population.

The case for improvement is clear. Good physical and mental health support are both essential for people living with HIV, for their wellbeing and long-term health outcomes. We hope this report will be a call to action for change and help drive forward improvements so there is consistent HIV mental health support across the country.

## 1.1 What is HIV?

HIV (Human Immunodeficiency Virus) is a virus which, when untreated, attacks the immune system – the body’s defence against diseases. There are more than 105,000 people living with HIV in the UK.

HIV can be passed on through some bodily fluids such as semen, vaginal fluids, blood, breast milk and rectal secretions. It cannot be passed on via saliva, urine or faeces. The most common way HIV is transmitted is through sex without a condom or without another form of protection such as the HIV prevention drug, PrEP. It also cannot be passed on if the partner living with HIV is on effective treatment.

HIV stays in the body for life, but treatment can keep the virus under control and the immune system healthy. HIV treatment is extremely effective and most people now start treatment as soon as they are diagnosed. Someone living with HIV, diagnosed in good time and on treatment, can lead a full, active life with a normal life expectancy. Treatment reduces the level of HIV in the body to what is called an ‘undetectable viral load’. People living with HIV with an undetectable viral load (the vast majority of people with diagnosed HIV in the UK) cannot pass the virus on to sexual partners. This is known as U=U (Undetectable = Untransmittable).

In the UK, the vast majority of people living with HIV are diagnosed and on treatment. 97% of those on treatment are virally suppressed, meaning that 89% of all people living with HIV in the UK can’t pass it on. HIV today is a manageable long-term condition. However, it remains uniquely stigmatised and challenging to live with.

**HIV today is a manageable long-term condition. However, it remains uniquely stigmatised and challenging to live with.**



## 1.2 What is IAPT?

Improving Access to Psychological Therapies (IAPT) is a programme started in 2008 with the aim of improving the quality and accessibility of mental health support in England.

IAPT services deliver psychological therapies, also known as talking therapies, to support people experiencing depression and anxiety disorders. It provides evidence-based therapies approved by NICE (National Institute for Health and Care Excellence), such as Cognitive Behavioural Therapy (CBT) and Person-Centred Experiential Counselling for Depression (PCE-CfD). Less common interventions include interpersonal therapy (IPT) and eye movement desensitisation and reprocessing (EMDR).

IAPT services can normally be accessed either by self-referral or via referral from a GP or other healthcare professional. While patients may present with more than one mental health problem, an initial assessment serves to identify the main problem the patient would like to work on, which in turn determines the intervention provided. Services operate using a stepped-care model, whereby patients are offered the least intrusive intervention appropriate for their needs first.

On its own terms IAPT has been successful. In 2019/20, 1.69 million referrals to IAPT were made, with 1.17 million of those starting treatment. IAPT sets itself the target of achieving a minimum rate of ‘recovery’ of 50% for all individuals completing treatment. According to the most recent data published by IAPT, 51.1% referrals moved to recovery in 2019/20.<sup>4</sup> These are positive outcomes. Despite this, there are concerns about how IAPT works in practice, if it is effective in meeting people’s needs, and specifically, if it is suitable for people living with HIV.

<sup>4</sup> NHS Digital, 2020, Psychological Therapies: Annual report on the use of IAPT services, England 2019-20 [Available at: <https://files.digital.nhs.uk/B8/F973E1/psych-ther-2019-20-ann-rep.pdf>]

## 1.3 Rationale for this project

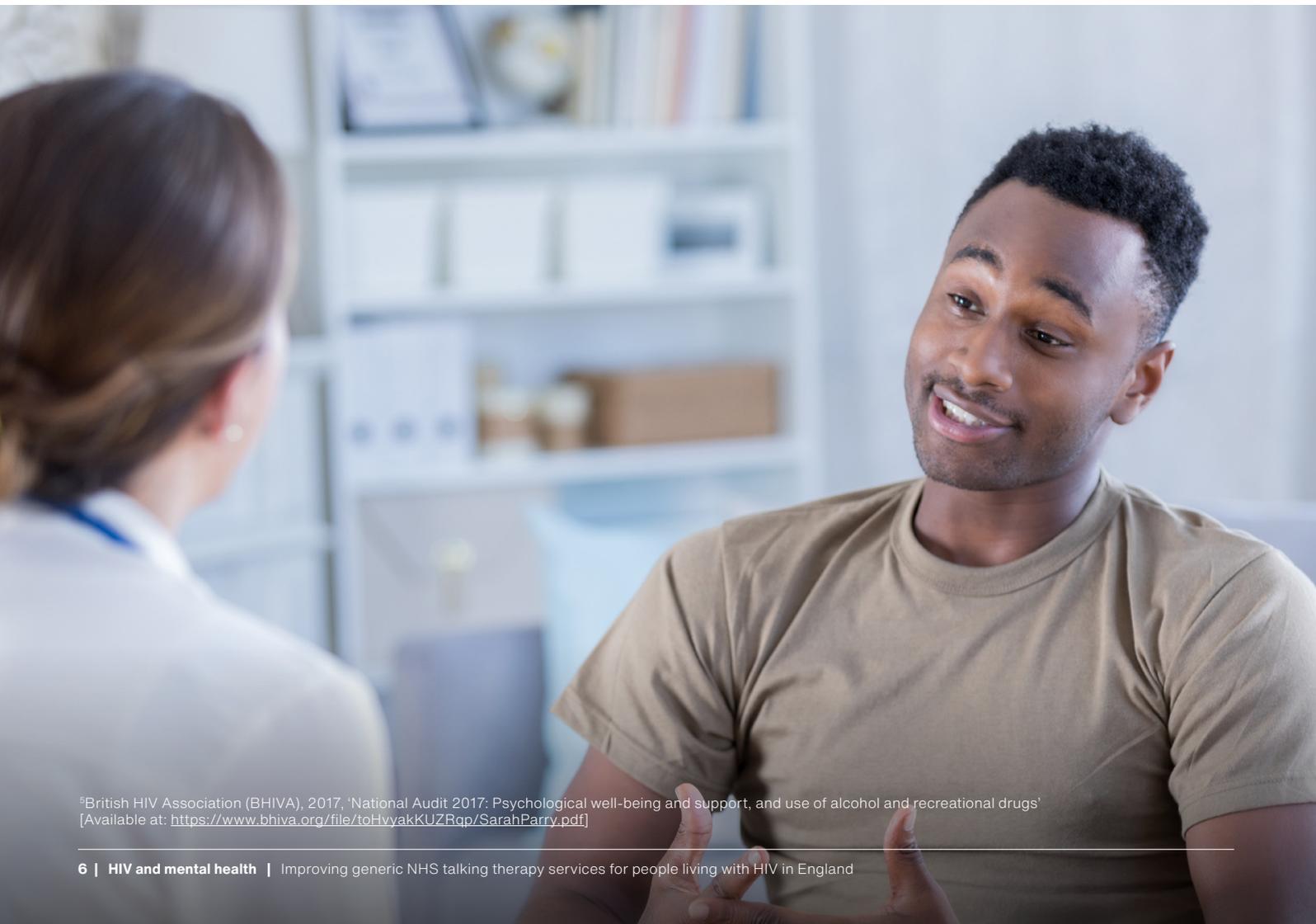
People living with HIV have traditionally accessed mental health support either through HIV clinics or voluntary sector HIV support services. These are often excellent sources of support. HIV clinics understand the needs of people living with HIV and can facilitate the provision of HIV care and psychological support in the same location. Voluntary sector HIV support services provide a wide range of interventions including counselling, psychotherapy, and psychosocial interventions such as peer support, recognised as being highly effective for people living with HIV. Yet in spite of this, such services are not reaching everyone who needs them due to a lack of funding.

A 2017 audit by the British HIV Association (BHIVA) found that nearly 40% of HIV clinics do not have access to a psychological or mental health professional within their multidisciplinary team (MDT).<sup>5</sup> At the same time, HIV support services are not widely available outside of cities, and cuts to public health budgets – compounded by the lack of a clear commissioning home for HIV support services – have resulted in many services being decommissioned. Access to HIV-specialist mental health services, be they in clinics or

community settings, has therefore become a postcode lottery.

In lieu of specialist services, IAPT has been proposed by some local commissioners as a good alternative. But generic mental health services are not routinely trained in HIV or the impact that HIV stigma can have on mental health, or on the intersecting issues faced by the key populations affected by HIV in England. Furthermore, it has been suggested that the lack of HIV specialism within generic mental health services and fears of HIV stigma within the health system can act as a real deterrent to vulnerable people accessing the help they need.

This project therefore set out to investigate these issues and the suitability of IAPT services for people living with HIV. It also aimed to outline where improvements can be made and to propose a series of recommendations to improve IAPT services for people living with HIV to ensure that they are well equipped to meet the needs of those who could benefit from interventions of this type.



<sup>5</sup>British HIV Association (BHIVA), 2017, 'National Audit 2017: Psychological well-being and support, and use of alcohol and recreational drugs' [Available at: <https://www.bhiva.org/file/toHvyakKUZRqp/SarahParry.pdf>]

## 1.4 Methodology

### Project advisory group

We convened a project advisory group in late 2020. The group included people living with HIV, HIV support services, clinical psychologists specialising in HIV, mental health charities, an HIV specialist psychiatrist and an IAPT course tutor. We conducted interviews with each member of the advisory group, consulted them on the development of a survey for people living with HIV, and held a roundtable meeting in June 2021 to get feedback on the initial findings from our research and draft recommendations. The group have also supported the development of this report.

### Survey of people living with HIV

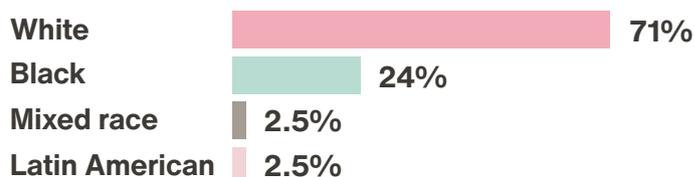
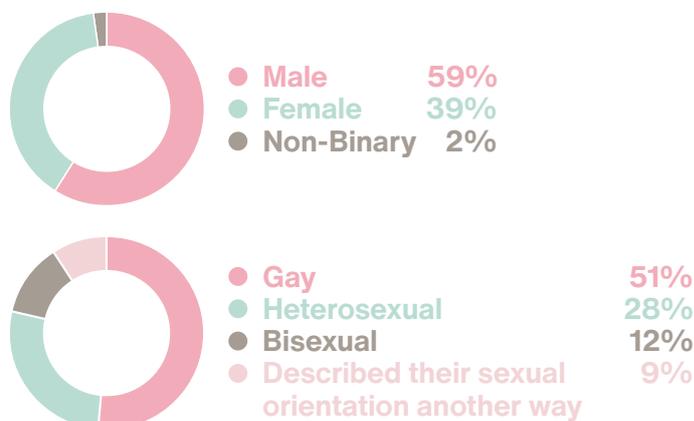
To gather evidence of the effectiveness of IAPT services for people living with HIV we conducted an online survey. The survey was promoted through a broad range of channels including social media platforms, existing National AIDS Trust networks, the project Advisory Group, HIV Prevention England, key activists, and organisations working with people living with HIV throughout the UK.

The survey was designed to capture the experiences of people living with HIV in England who had accessed IAPT. It was open to people who had accessed NHS talking therapies more widely, but questions within the survey itself identified who had accessed IAPT specifically.

203 adults living with HIV in England responded to the survey, of whom 123 had accessed talking therapy provided by the NHS. Of this group, 58 participants had accessed IAPT services. Unless otherwise specified, survey statistics cited in this report are based on this group of 58.

### i The demographics were fairly reflective of the population living with HIV in England:

**95% were of working age**  
(aged between 26 and 65).  
The remaining participants were aged 65+.

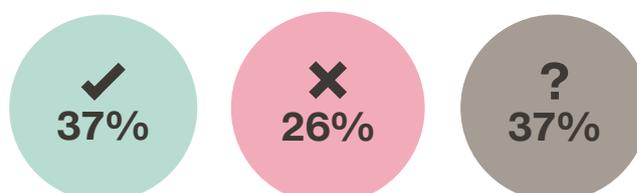


### ? We also asked participants information about their primary and HIV healthcare:

**+ All participants were registered with a GP, and the vast majority (95%) reported that their GP was aware of their HIV status.**



### ? Does your clinic have in-house psychological support?



## Interviews

Following the survey, we conducted in-depth interviews with 12 respondents who indicated that they were willing to be contacted. Interview participants were selected on the basis of their survey responses and the value we deemed could be added by discussing their experiences in more detail.

10 of the interviewees had accessed IAPT services, with a mixture of positive and negative experiences. This group represented the main demographics who responded to our survey: gay white men and black heterosexual women. We also interviewed 2 trans people in light of the particular challenges to accessing healthcare faced by the trans community. One interviewee had accessed psychological therapy via their HIV clinic and the other through a trans-led wellbeing and sexual health service.

## Limitations of our research

The findings of our survey and interviews cannot claim to represent the experiences of all people living with HIV. In addition to the limited sample size, not all populations living with HIV were represented; for example, we did not hear from any men from ethnic minority groups who also identify as gay, or anyone aged 18-25 years old. It is not clear why this was the case, but it is important to recognise that different populations may experience the intersection of HIV and mental health in specific ways, or face specific barriers to accessing services.

The online nature of the survey may have excluded some people who were unable to respond in this way, whether due to lack of internet, technical illiteracy, or lack of privacy. The impact of this may have been mitigated by the wider shift to online working during the COVID-19 pandemic, though it is equally possible that digital fatigue during this period deterred some people from taking part. We are aware for example of numerous other surveys aimed at people living with HIV that were circulating around the same time.

It is significant to note that our survey predominantly captured the experiences of people who have accessed NHS psychological therapy services. It is therefore limited in making conclusions about the acceptability of these services to people living with HIV who have not already accessed them. The people who responded to our survey were at least willing to access generic mental health services, which may not be the case for everyone with HIV.



## 2. Summary of recommendations

### NHS England

- NHS England and Health Education England to ensure basic training on HIV, HIV stigma and 'talking about sex' is added to the national curriculum for all IAPT workers.
- Analysis to be conducted of the potential impact of developing HIV pathways within IAPT-LTC. This could be via an evaluation of pilot services in areas with a high or extremely high prevalence of HIV.
- HIV to be added to the list of core conditions covered by the IAPT for Long-Term Conditions (IAPT-LTC) model, enabling IAPT-LTC services to develop specific HIV pathways and ensuring that services are better integrated with HIV treatment and care.
- NHS England and Health Education England to add specific training on the provision of psychological support to people living with HIV to the national curriculum for IAPT-LTC staff. Development of this training should draw on the Standards for psychological support for adults living with HIV and involve consultation with the British Psychological Society, British HIV Association, and Medical Foundation for AIDS and Sexual Health.
- IAPT staff must be enabled to deliver culturally competent services that reflect the needs of their local populations. This should be supported by the involvement of relevant populations in the design and delivery of services and the provision of staff training on the intersection of mental health with other forms of marginalisation.
- NHS England should assess whether provision of psychological support should form a part of the national service specification for HIV services given the high prevalence of mental health issues among people living with HIV.

### IAPT Services

- IAPT to review staff recruitment policies and actively seek to increase staff diversity and representation.
- IAPT services must develop clear action plans as to how inequalities will be addressed on an annual basis. This should be built into commissioning and action plans should be published online.
- IAPT services must develop clear referral pathways with relevant services including clinical HIV services, clinical/health psychology and liaison psychiatry teams, voluntary sector HIV support services, and drug and alcohol services.
- IAPT services to review and clarify their eligibility criteria to ensure that patients who could benefit from support are not unreasonably excluded or deterred from accessing it.
- Data sharing practices and policies should be made clear to patients throughout the IAPT pathway, recognising the particular confidentiality concerns of people living with HIV. This may require reviewing data sharing practices and working with HIV services to enable patients to determine who their records are shared with.



## Local commissioning bodies

- Integrated Care Systems (ICSs) should ensure collaboration between all bodies commissioning mental health services within their footprint, so that comprehensive pathways for the full range of mental health support are available for people living with HIV, whatever their particular needs.
- Voluntary sector HIV support services should be commissioned in line with need, both to meet needs which generic services are unable to provide appropriately (including peer support), and also to complement, train and work alongside generic provision.
- Greater flexibility as to the types and lengths of treatment provided by IAPT services to be offered to patients living with HIV, in line with the principle of offering patients meaningful choice about their treatment.

## HIV clinics and clinicians

- IAPT should be better promoted within the HIV system to improve awareness and understanding of talking therapies. Communication about IAPT services should avoid jargon and acronyms and make clear exactly who and how services can help.
- All HIV clinics should include a psychologist/mental health professional on their multi-disciplinary team (MDT).
- Increased implementation of the BHIVA Standards of Care and Monitoring Guidelines is needed across HIV services in the UK, ensuring that more HIV services are regularly assessing mental health needs among patients, that all HIV services have clear referral pathways into mental health care, and that more HIV services have a designated clinical lead for psychological support.

## NHS Digital

- Data sharing practices and policies should be made clear to patients throughout the IAPT pathway, recognising the particular confidentiality concerns of people living with HIV. This may require reviewing data sharing practices and working with HIV services to enable patients to determine who their records are shared with.
- Data routinely published by IAPT regarding service activity and outcomes should differentiate between IAPT-LTC and generic IAPT services.
- HIV should be added to the list of discrete long-term conditions that are monitored under the 'Long term conditions' variable in IAPT reporting.
- The experience of trans people accessing IAPT should be monitored by adding 'Trans' as a gender variable in IAPT data collection and reporting.
- IAPT should assess waiting times against referrals entering treatment, rather than those completing a course of treatment, and review the way that appointment types are being recorded.

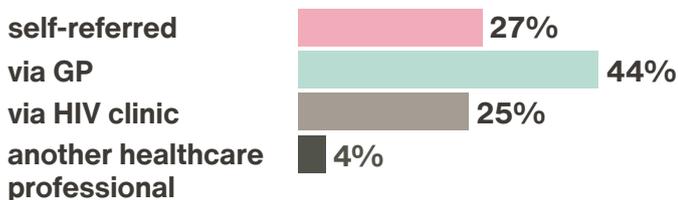
## Department of Health and Social Care

- The Department of Health and Social Care should ensure that improvements to mental health provision for people living with HIV is included in the upcoming HIV Action Plan.

# 3. Experiences of IAPT

## 3.1 Routes of access and waiting times

### ? How did you access IAPT?



### i Waiting times

**52%**  
Around half of people were seen within 8 weeks of referral

**34%**  
A third waited more than 12 weeks to be seen

**10%**  
1 in 10 people waiting for more than a year to be seen

As expected, the most common routes of entry to IAPT services were via a GP (44%) and self-referral (27%). It is notable however that a quarter of respondents were referred by their HIV clinic, suggesting the existence of functioning referral pathways between specialist and generic services in some areas. It is not clear whether such referrals reflect strategic decision-making about where patients' needs can best be met or a lack of capacity to support patients in-house.

Over a third of respondents reported waiting more than 3 months to be seen, and 1 in 10 waited more than a year. This leaves people who may be extremely vulnerable without adequate support. Many respondents also identified long waiting times as a barrier or deterrent to accessing mental healthcare.



**“[I] don’t want to put myself in a raw and vulnerable position to be told I have to go on a waiting list. I am already in crisis at that point.”**

#### Survey respondent

The national standard for waiting times set by IAPT is that 75% of referrals should have their first treatment session within 6 weeks, and 95% within 18 weeks. This is based on evidence that patients are more likely to benefit from a course of treatment if it is delivered promptly.<sup>6</sup> To gain further insight into this, Centre for Mental Health have recently called for IAPT to link waiting times to patient outcomes in their reporting (something that is not done currently).<sup>7</sup>

Although the data collected by our survey is limited, a simple comparison (not controlling for other variables) demonstrates considerably better outcomes for people who were seen promptly, compared to those with longer waits. Of those who started treatment within 8 weeks of being referred, two thirds (66%) reported an improvement in their mental health as a result of therapy. This compares to only two fifths (41%) of those who waited more than 8 weeks to receive support. In addition to supporting better mental health outcomes, faster access to psychological support reduces other negative outcomes such as non-adherence to ART (HIV medication), clinical complications and hospital admissions, and their associated costs to the health service.<sup>8</sup>

<sup>6</sup> NHS, 2018, The Improving Access to Psychological Therapies Manual [<https://www.england.nhs.uk/publication/the-improving-access-to-psychological-therapies-manual/>]

<sup>7</sup> Centre for Mental Health, 2021, Now or never: A systemic investment review of mental health care in England [<https://www.centreformentalhealth.org.uk/publications/now-or-never/>]

<sup>8</sup> BHIVA, British Psychological Society (BPS) and Medical Foundation for AIDS and Sexual Health (MedFASH), 2011, Standards for psychological support for adults living with HIV [<https://www.bhiva.org/standardsforpsychologicalsupport/>]

## 3.2 Mental health support needs

The most common problems experienced were:

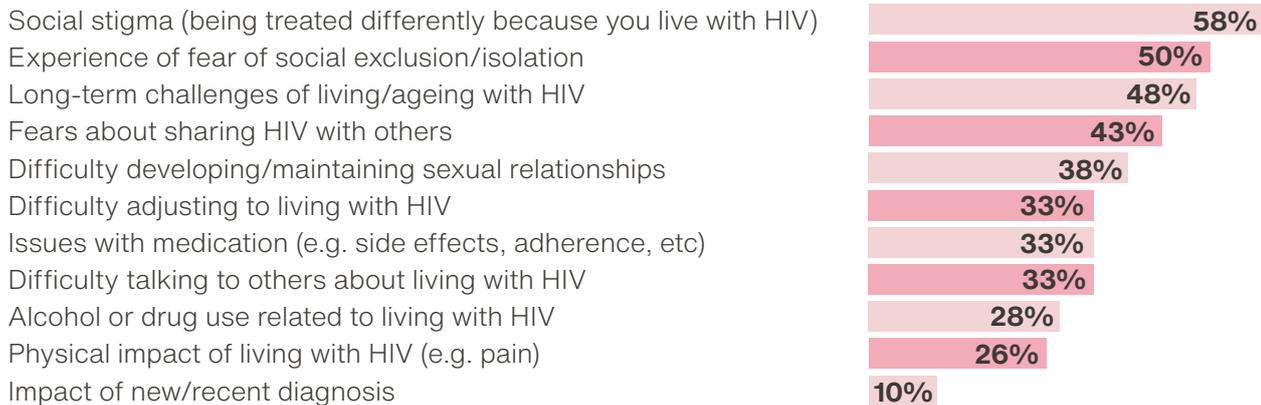


but significant numbers also reported:



4 in 5 people reported that the problem/s were directly (19%) or somewhat (60%) related to living with HIV.

### ? How was it related to living with HIV?



The most common mental health problems experienced were depression and general anxiety. Many respondents indicated that they sought help for multiple concurrent problems, for example generalised anxiety and post-traumatic stress disorder (PTSD). This is not uncommon for people experiencing mental ill-health.

The vast majority of people living with HIV who accessed IAPT did so for reasons related to living with HIV. Most common among these were social stigma (being treated differently because you live with HIV) and experience or fear of social isolation, with over half of respondents reporting each. The pervasiveness of HIV stigma is well-acknowledged, and this data further demonstrates the negative impact of this on the mental health of those living with HIV.

In addition to reasons that we can describe as actual or perceived stigma, significant numbers reported long-term challenges of living/ageing with HIV (48%) and issues with medication (33%). This reflects the ageing population of people living with HIV and the specific ways that this can impact upon mental health. It also highlights that while treatment is now highly effective and allows people to live long and healthy lives, it is not without difficulties.

Interestingly, only 1 in 10 people reported that their mental health problems were related to the impact of their diagnosis. This is not to say that their diagnosis did not impact upon their mental health, but rather that it was not the reason for them

accessing IAPT. Possible reasons for this include initial support from HIV clinics upon diagnosis (e.g. from health advisors or HIV specialist nurses), or an initial reluctance/inability to engage with services or share their HIV status with others.

It is notable that over a quarter (28%) of respondents reported alcohol or drug use related to living with HIV as a factor impacting upon their mental health. Use of drugs and alcohol can sometimes be coping strategies but can themselves become detrimental to wellbeing. IAPT services are not designed to address drug and alcohol misuse and instead tend to signpost relevant patients to drug and alcohol services. These services are in turn often unable to support people with mental health issues, resulting in a gap in provision people can fall through. It is possible that alcohol/drug use reported by respondents was not considered by IAPT services to meet the threshold of 'problematic' use, or that people simply did not disclose or discuss this with their therapist at the time.



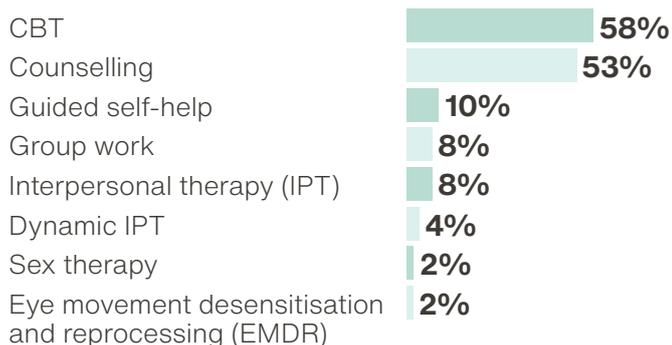
**"I was at a point where I was taking a lot of drugs and drinking a lot, and I didn't tell [the therapist] about it because I didn't want it to get back to my employer. I wasn't honest in CBT - part of the reason I was so anxious was because I was high all the time and the reason why I was high all the time was because I was trying to control my anxiety."**

Interview participant

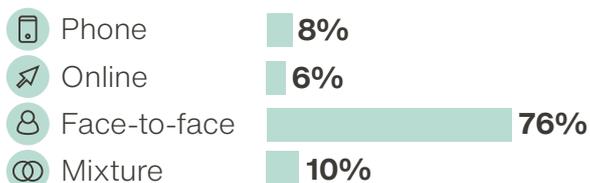
A few respondents mentioned other HIV specific experiences, including self-blame regarding the acquisition of HIV, guilt and shame regarding risk-taking, and loss of friends/lovers/peers to the virus or as a result of stigma. More than one respondent also reported the impact of working in the HIV sector and supporting other people living with HIV, indicating a need for workplace support.

### 3.3 Delivery of therapy

#### ? What type of therapy did you receive?



#### ? How was it delivered?



A high number of respondents reported 'counselling' being offered considering IAPT's typical focus on CBT. This may reflect the high proportion (85%) of people who reported experiencing depression, for which IAPT's counselling provision is specifically suitable. It is also possible that the definition of counselling used in the survey was selected by people as an umbrella term for a broader range of treatments.

The majority of respondents received therapy face-to-face (i.e. in person), with just less than a quarter of people receiving it remotely (via telephone or online) or in a mixture of different ways. The exception were those who had received therapy "within the last year", which coincided with the emergence of the COVID-19 pandemic and national lockdowns which rendered face-to-face therapy impossible.

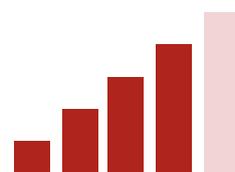
Of those who had accessed therapy remotely, a majority (61%) said that they felt comfortable accessing it in this way, while the remainder said they were not comfortable (28%) or that they were unsure (11%). When all respondents to our

survey (including those who had accessed other non-IAPT forms of NHS talking therapy) were asked if they would feel comfortable accessing therapy remotely in future, just over half (52%) said yes while around a quarter (26%) said no and the remainder were unsure. This is important to recognise as we return to pre-COVID-19 ways of life and some services may be tempted to continue providing support more remotely.

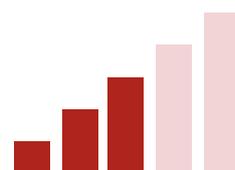
### 3.4 Impact of IAPT support

#### ? Severity of mental health problems at the start and end of therapy

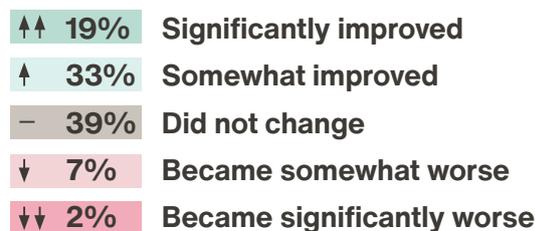
**Start of therapy**  
4/5 (average 3.9)



**End of therapy**  
3/5 (average 2.8)



#### ? Change in mental health as a result of the therapy?



IAPT measures outcomes in terms of 'recovery', which is achieved where a patient's symptoms are severe enough to be defined as a clinical case at the start of their treatment and not severe enough to be defined as a clinical case at the end of treatment. As this terminology is not necessarily used by patients, our research instead relied on self-reported outcomes. To do so we asked respondents to self-assess the severity of their mental health problem(s) before and after therapy.

Self-perceived severity of mental health problems before therapy was high, averaging 3.9 on a scale from 0-5. This is interesting given the traditional focus of IAPT as a service aimed at those with mild-to-moderate cases of depression and anxiety disorders – something

that IAPT leadership figures have disputed.<sup>9</sup> After treatment the self-perceived severity of mental health problems decreased, averaging 2.8. It is important to note that while this reflects an improvement, the average person exiting treatment still considered themselves to have relatively severe mental health needs. In addition to ‘recovery’, IAPT also measures ‘reliable improvement’ – whereby there is a significant improvement in a patient’s condition following a course of treatment, measured by the difference between their first and last scores on questionnaires tailored to their specific condition. As we could not tailor this to specific conditions, we asked respondents to self-assess the change in their mental health resulting from therapy.

Just over half (52%) of people reported that their mental health had improved to some degree as a result of therapy (19% significantly and 33% somewhat improved). 2 in 5 (39%) reported that their mental health did not change, and almost 1 in 10 reported that it became worse (7% somewhat and 2% significantly worse). These findings are very concerning, especially given the low proportion of respondents who were offered further support at the end of their course of therapy.

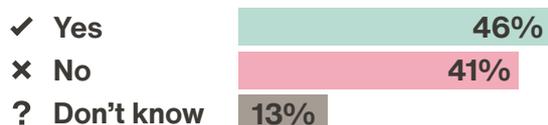
In comparison, NHS Digital reports that in 2019-20 67% of IAPT referrals finishing a course of treatment nationally showed reliable improvement (as reported by NHS Digital in 2019-20).<sup>10</sup> It is important to note that these statistics are not directly comparable to ours as the terms and method of data collection differ, but the disparity highlights an inconsistency between self-perceptions and clinical assessments of improvement, or significantly worse outcomes among people living with HIV than the general population.

### 3.5 Patient satisfaction

② **Could your experience of NHS talking therapy have been improved in any way?**



② **Would you be happy to use the same service again?**



Patient satisfaction is important, not least for improving future access and acceptability. When asked if their experience of therapy could have been improved in any way, over three quarters (78%) of respondents who’d accessed IAPT answered yes. The ways that people felt it could be improved will be explored throughout this report, and include: better understanding of HIV and its impact upon mental health; a more person-centered approach to care; cultural competency and improved representation; opportunities for peer support; and greater choice and flexibility within services.

Disappointingly, less than half (46%) of respondents indicated that they would be happy to use the same service again if they were to experience mental health problems in the future. This is particularly concerning for people living with HIV for whom IAPT is the only available source of mental health support. Patients who would not be willing to use the same service again talked about issues with the type(s) of therapy available, long waiting lists and slow referral processes, feelings of not being valued, and the length of treatment not being sufficient. The following sections of this report outline the areas of improvements that could be made to address these and other issues.

**Disappointingly, less than half (46%) of respondents indicated that they would be happy to use the same service again if they were to experience mental health problems in the future.**

<sup>9</sup> Clark DM. ‘A guide to improving Access to Psychological Therapies services’ NHS England blog [<https://www.england.nhs.uk/blog/a-guide-to-improving-access-to-psychological-therapies-services/>]

<sup>10</sup> NHS Digital, 2020, Psychological Therapies: Annual report, opt. cit.

## 4. Areas for future improvements to IAPT services

### ② How would you describe the therapist's understanding of HIV?

☆☆☆☆☆	Very Good	21%
☆☆☆☆	Quite good	27%
☆☆☆	Average	27%
☆☆	Poor	9%
☆	Very Poor	15%

#### 4.1 More HIV literate services

The ways that HIV intersects with mental health are complex. Both HIV and mental health problems are highly stigmatised, associated with compounding factors such as loneliness and isolation, and disproportionately affect population groups already marginalised in other ways, such as Black and minority ethnic communities and LGBT people. The impact of an HIV diagnosis itself can be traumatic, and people with mental health problems are more likely to acquire HIV.<sup>11</sup>

These complexities pose a challenge to generic mental health services and many people living with HIV will require specialist support. Those with less complex mental health needs however, and those who do have the option of accessing specialist support, will likely rely on IAPT. HIV may still be an important factor in the mental health needs of this cohort. It is therefore vital that IAPT services are equipped to support them effectively.

##### 4.1.1 A better understanding of HIV stigma

Despite huge progress in treatment and care, HIV remains a highly stigmatised condition.

One in five respondents to the HIV Stigma Index in 2015 had experienced verbal harassment or threats.<sup>12</sup> A third reported having their HIV status disclosed without consent by a friend or a family member, and one in five also reported being treated differently by a GP. This can unsurprisingly have a detrimental impact on mental health, contributing to feelings of isolation and low self-worth. Societal stigma can also lead to self-stigma (or perceived stigma), whereby people living with HIV internalise negative messages about HIV, leading to feelings of shame and even suicidal thoughts.

<sup>11</sup>APPG on HIV & AIDS, 2019, The Missing Link, op. cit.

<sup>12</sup>The Stigma Index UK, 2015 'Stigma Survey UK 2015', 2015 [<http://www.stigmaindexuk.org/reports/2016/NationalReport.pdf>]

<sup>13</sup>Changing Perceptions, 2018, Talking about HIV and Attitudes [<https://changingperceptions.co.uk/about-us/reports/>]

### ② Did you feel the therapist understood the ways in which HIV affected mental health?

✓ Yes	64%
✗ No	36%



**“There is still a significant amount of regret I share, I hold on to, really, about the process by which I got it, and the effects it had on my life at the time. The shame I’m living with. Also, since getting it there have been times when I’ve been made to feel very ashamed about it. A real stigma is carried with it, even to the people closest to me.”**

Interview participant

Unfortunately, the healthcare system is itself a site of HIV stigma in England. PHE’s Positive Voices survey in 2017 found that a third (35%) of people living with HIV had been worried that they would be treated differently to other patients and 14% had actually experienced discrimination in a healthcare setting.<sup>13</sup> 18% had avoided healthcare when they needed it, and 11% of people with HIV had actually been denied or refused a treatment or procedure that they needed.



**“My experience of the medical profession is that the prejudice has come off of dentists and even health care workers, that’s probably for me where I’ve been most stigmatised.”**

Interview participant

Unfortunately, our survey found evidence of significant stigma within IAPT itself. A quarter (24%) of respondents felt that their HIV status negatively affected the way that they were treated. When asked to explain, respondents reported visibly negative reactions to sharing their HIV status, feelings of being judged, and inappropriate questions asked by therapists about sexual risk and recklessness.

## Survey respondents and interview participants recounted frustration at having to repeatedly explain what it means to live with HIV and the time this took away from discussing other matters.



**“I felt like my therapist was keeping notes on the numbers of sexual partners I was having because she seemed to think I was spreading it around. I kept trying to explain what U=U means, but it felt like it wasn’t going in.”**

**Survey respondent**

This stigma not only impacts upon the quality of life and mental health of people living with HIV, it can also deter people from getting help. Again, the findings of our survey support this. Less than half (46%) of respondents indicated that they would be happy to use the same service again if they were to experience mental health problems in the future.



**“She [the therapist] couldn’t see me, I felt that she was uncomfortable and going through a process rather than dealing with a person. I felt I began behaving in ways to make her feel comfortable and minimise my existence.”**

**Survey respondent**

The survey also captured limited data on those who responded to the survey but had not accessed therapy provided by the NHS. These respondents were asked why they had not used NHS services. Of those who had wanted talking therapy but hadn’t accessed it, 75% reported that they wouldn’t want to access a therapist outside of their HIV clinic. This reveals the limitations of relying on generic mental health services to provide psychological support to people living with HIV.

### 4.1.2 Improving HIV literacy

The importance of HIV literate mental health services has been made clear in national guidance and policy recommendations.



**“The mental healthcare professional working with someone living with HIV should have up-to-date HIV-specific knowledge and cultural competencies (including lifespan and demographic variables, and antiretroviral psychotropic side-effects and interactions), access to research literature, training, supervision or consultation as necessary.”<sup>14</sup>**

#### **BHIVA Standards of Care for People Living with HIV 2018**

As we have seen, HIV is often directly or indirectly relevant to the mental health needs of people living with HIV. Understanding this relationship enables therapists to provide appropriate support, whereas a lack of HIV literacy can be frustrating or even actively harmful for patients. Survey respondents and interview participants recounted frustration at having to repeatedly explain what it means to live with HIV and the time this took away from discussing other matters. Examples were provided of therapists expressing incorrect or outdated opinions about HIV, and even giving erroneous advice regarding HIV transmission and personal responsibilities.



**“I spend my entire working life and personal life explaining to people what HIV is, why it’s not infectious when on medication, etc. I really didn’t want to have to educate somebody else, who was meant to be supporting me. And I did, like I said, and she was fine... but there’s no chance I’m having therapy with her again. She made me feel uncomfortable in that room, because I had to educate her and that was frustrating.”**

**Interview participant**

<sup>14</sup>BHIVA, 2018, Standards of Care for People Living with HIV 2018 [<https://www.bhiva.org/standards-of-care-2018>]

The 2011 Standards for the Psychological Support of Adults Living with HIV (produced by the British Psychological Society (BPS), Medical Foundation for AIDS & Sexual Health (MedFASH), and BHIVA) require that “All individuals requiring psychological support should have this provided by skilled practitioners who have been appropriately trained and have demonstrated the necessary competencies.”<sup>15</sup> While the authors recognise that generic frameworks for psychological support may be relevant for people living with HIV, the unique aspects of living with HIV mean that “additional competencies are also needed by practitioners at all levels.”



**“I think it’s important for someone who’s treating a person living with HIV... just to know about the fact that HIV stigma exists and what that can do in a person’s mind... for some people that might be at the top of their mind, for other people it might be deep down.... I think for a therapist it would be important to understand just how that whole process of stigma works and how you can take that on and internalise it.”**

**Interview participant**

The IAPT model has clear limitations in understanding the lived experience of people living with HIV. It is not, for example, designed to address co-morbidities around stigma, drug and alcohol use and sexual risk, and these matters do not form part of the national curriculum for training IAPT workers. Neither do HIV, psychosexual problems or ‘talking about sex’. This led the APPG on HIV & AIDS’ 2019 report on HIV and mental health to conclude:



**“Due to the level of stigma that people living with HIV can experience, both in society and sometimes within the healthcare system itself, IAPT workers will require training in HIV specific issues. Mainstream services need to demonstrate their ability to work with people living with HIV and help service users feel comfortable talking about their status and associated issues.”<sup>16</sup>**

The lack of HIV literacy in IAPT services was raised as a key concern by almost all stakeholders spoken to during the development of this report, including clinical psychologists, HIV support services, and people living with

HIV. The findings of our survey demonstrate that this is a pertinent issue, with 82% of respondents reporting that they talked to their therapist about living with HIV. This roughly correlates to the four fifths of respondents who reported that the problem/s they were experiencing were directly (19%) or somewhat (60%) related to living with HIV.

Just over half (52%) of respondents felt that their therapist had a good understanding of the problem(s) they were experiencing all of the time (20%) or most of the time (32%), while around a quarter (28%) answered “sometimes, but not always.” 1 in 5 people felt that their therapist did not have a good understanding of their problem(s). When asked to elaborate, this group cited outdated understanding of HIV; limited understanding of LGBT issues; an unwillingness to adapt to specific needs; and an emphasis on the provision of coping strategies rather than the exploration of problems. People who responded positively talked about therapists being empathetic and able to find areas of common ground, thus mitigating a lack of shared identity. Others stressed that their therapist was well-meaning but constrained by time restraints and requirements for assessments and “homework.”

Of those who did speak to their therapist about living with HIV, just under half described their therapist’s understanding of HIV as quite good (27%) or very good (21%). Around a quarter (27%) reported their therapist’s understanding was average, while a further quarter reported that understanding was poor (9%) or very poor (15%). Given the relevance of HIV to problems faced by the vast majority of people living with HIV accessing IAPT, this is not good enough. When presented with the statement ‘It is important that any therapist I see has a good understanding of HIV’, 67% strongly agreed and 30% agreed.



**“The bottom line is I felt like I was being judged for being [HIV] positive, that because she couldn’t come out of her mindset into mine, because she couldn’t see it from an HIV point of view, that her perspective was still very much society’s perspective, which is that people with HIV are somehow bad or wrong or morally bankrupt.”**

**Interview participant**

<sup>15</sup>BHIVA, BPS & MedFASH, 2011, Standards for psychological support, op. cit.  
<sup>16</sup>APPG on HIV & AIDS, 2019, The Missing Link, op. cit.

Just under two thirds (64%) of respondents felt that their therapist understood the ways in which HIV affected mental health. In contrast to this, all the respondents agreed (21% agree, 79% strongly agree) with the statement: “It is important that any therapist I see has a good understanding of the ways that HIV can affect mental health.” These findings support existing recommendations that providers of psychological support to people living with HIV possess at least a basic understanding of HIV and its impact upon mental health.

The importance of HIV awareness within the health system is not unique to mental health services. The 2020 HIV Commission recommended that “as more people living with HIV access non-specialised healthcare, training on HIV and sexual health should be mandatory for the entire healthcare workforce to address HIV stigma and improve knowledge of indicator conditions.”<sup>17</sup>

IAPT is by definition a generic service and the national IAPT curriculum cannot include training on the specific impact of each and every physical health condition on mental health. However, the impact of HIV and HIV stigma on mental health is arguably unique, and our research found overwhelming support among people living with HIV for improved understanding of HIV within IAPT services.

Providing basic training on HIV and HIV stigma, gender and sexual diversity, and ‘talking about sex’ for all IAPT workers would help to improve this current situation. These topics could be included in the training programme section on ‘Equality and cultural competence,’ and is an opportunity for IAPT services to not only deliver better care for people living with HIV but also support national ambitions to end HIV stigma.

### Recommendations:

- NHS England and Health Education England to ensure basic training on HIV, HIV stigma and ‘talking about sex’ is added to the national curriculum for all IAPT workers.”

## 4.2 HIV as part of IAPT for long-term conditions

### 4.2.1 The IAPT-LTC model

The implementation plan for the Five Year Forward View for mental health set out the ambition that, by 2020/21, 1.5 million people a year will access psychological therapies through IAPT, with a focus on those with long-term conditions.<sup>18</sup> 40% of people with depression and anxiety disorders also have a long-term condition, while around 30% of people with a long-term condition have mental health co-morbidities.<sup>19</sup> Since 2018 all clinical commissioning groups in England have additionally been required to offer IAPT services integrated with physical healthcare pathways, recognising the benefits of providing joined-up care. These services are known as IAPT for Long-Term Conditions, or IAPT-LTC.

Building on IAPT’s existing workforce and infrastructure, IAPT-LTC services target the needs of people who are experiencing mental health problems alongside long-term conditions. They do so by aiming to bring together mental and physical health providers to work in a coordinated way and by providing IAPT-LTC workers with top-up training on CBT in the context of long-term conditions.

A key principle of this model is the co-location of IAPT services with physical healthcare, requiring IAPT practitioners to work closely with physical health colleagues as well as generic IAPT services and other mental health teams such as clinical and health psychology services located in hospitals.

The benefits of integrating services in this way are set out in the IAPT-LTC Full Implementation Guidance, and include improved access, faster diagnosis, and cost-effectiveness. Evaluation of the ‘early implementer’ (i.e. pilot) IAPT-LTC services also demonstrated improved clinical outcomes compared to those experienced by people with long-term conditions in core IAPT services.

How IAPT-LTC services are integrated with physical health pathways varies. Services may be co-located in primary care, secondary care or community settings. An evaluation of the first wave of IAPT-LTC services found that services were co-located predominantly in GP clinics and community settings. These tend to be multimorbidity models (i.e. they see people experiencing a range of different long-term conditions), though staff may be integrated into community teams focusing on a specific disease group. This can facilitate joint

<sup>17</sup>HIV Commission, 2020, How England will end new cases of HIV: The HIV Commission Final Report & Recommendations [<https://www.hivcommission.org.uk/final-report-and-recommendations/>]

<sup>18</sup>NHS, 2016, Implementing the Five Year Forward View for Mental Health [<https://www.england.nhs.uk/publication/implementing-the-fyfv-for-mental-health/>]

<sup>19</sup>NHS, 2018, The Improving Access to Psychological Therapies (IAPT) Pathway for People with Long-term Physical Health Conditions and Medically Unexplained Symptoms [<https://www.england.nhs.uk/wp-content/uploads/2018/03/improving-access-to-psychological-therapies-long-term-conditions-pathway.pdf>]

working and care planning. Services may also have condition-specific ‘Champions’ who have a particular interest in a given condition and so may take on or supervise a lot of these cases, as well as delivering in-house training to the wider staff team.

Co-location of IAPT-LTC services in secondary care (i.e. hospitals) is also an option, with staff likely to be integrated into a condition-specific pathway. This is less common due to logistical challenges such as lack of available space and the use of different information systems. However, where co-location within secondary care has occurred it has enabled effective integration of care and good outcomes. Reported benefits include patient satisfaction, learning and training opportunities, shared screening tools, and significant physical health cost savings.

### Case Study

In Sussex the Time to Talk Health IAPT-LTC service is co-located within the diabetes team at Western Hospitals NHS Foundation Trust. The service saw a significant change in the Diabetes Distress Scale (DDS) among their patient cohort, as well as shared learning between staff.

While many of the evidence-based therapies used in IAPT services are similarly effective in people with and without long-term conditions, optimal outcomes are achieved when the delivery of psychological therapies takes account of the ways in which LTCs interact with mental health problems. This includes consideration of the impact of LTCs on presenting problems, support regarding self-management of LTCs, and modification of interventions.

To support this, all IAPT-LTC staff are required to receive top-up training (beyond that required of generic IAPT services) in additional competencies. This includes ‘underpinning competencies’ and ‘generic intervention skills for work with people with long term health conditions,’ as well as ‘evidence-based interventions for specific health conditions.’ These specific health conditions, for which IAPT-LTC staff receive specialist training, include diabetes and cancer among others.

Each of these conditions has a strong evidence base in terms of clinical outcomes and physical healthcare savings. HIV has not yet been considered within this framework.

### 4.2.2 Developing IAPT-LTC for HIV

Integrating IAPT and HIV care pathways and developing HIV-specific training for IAPT-LTC staff has the potential to increase the effectiveness and acceptability of IAPT services for people living with HIV.

One of the major barriers to accessing IAPT for people living with HIV is a reluctance to engage in generic services, so integrating care, and particularly co-locating mental healthcare in HIV services, could help to overcome this. This was a view shared by a number of stakeholders we spoke to, including clinical psychologists and people living with HIV.



**“I would definitely feel more at ease accessing such a service through my HIV clinic/hospital than via my GP. HIV awareness within community settings from my experience within my CCG appears lacking or outdated over a number of services.”**

#### Interview participant

It was suggested that the development of an HIV pathway within IAPT-LTC services would work best if it was seen as working with and in HIV clinics and support services. This would enable the provision of more joined-up care, shared learning between staff and effective multidisciplinary team working. It would also reassure patients that IAPT staff understood their specific needs.

Integrating IAPT within HIV care is not without challenges. These include a lack of appropriate physical space in HIV clinics, unfamiliarity with the IAPT model of care, and the use of different information systems (making the sharing of patient notes between physical and mental health services difficult). For integrated services to be effective also requires the buy-in of acute care teams that are often already overstretched, and collaboration with a wide range of healthcare professionals. All of this requires investment and commitment. However, these challenges are not unique to HIV and learnings from the development of existing long-term condition pathways could be utilised.

The findings of our research suggests that there is also a case for adding HIV-specific training to the IAPT-LTC curriculum.



**“Competencies around long-term conditions in general are not sufficient, because HIV is unique in its level of stigmatisation and the particular groups it disproportionately affects - each with their own inequalities.”**

**Clinical psychologist**

Providing IAPT-LTC staff with training on mental health support in the context of HIV would better equip them to support the needs of people living with HIV, and also increase confidence in the service.



**“the ideal [IAPT-LTC] model would be to train them up and then embed them within the HIV team. So IAPT fund it, but the worker sits within the medical team so that they have the connections to give that person wrap-around care. Within HIV there is a need for people to feel safe and know that their specific needs (including around confidentiality) are understood.”**

**Clinical psychologist**

The *Standards for the Psychological Support of Adults Living with HIV* provide a minimum set of competencies which we recommend forms the basis of any HIV-specific top-up training for IAPT-LTC workers. At the time of writing, these standards are in the process of being reviewed, led by the British Psychological Society’s Faculty for HIV & Sexual Health in partnership with BHIVA, NHIVNA (National HIV Nurses Association) and UK-CAB (UK Community Advisory Board). This will likely add to the evidence-base regarding psychological interventions for people living with HIV, and we recommend that NHS England draws on this resource and involves the British Psychological Society in the design of any HIV-specific training.

We recognise that local evaluations will need to be conducted, taking into consideration activity, outcomes, and the impact of services on the wider health system including HIV care. We recommend that any piloting of IAPT-LTC HIV pathways should be done in areas with a high or extremely high prevalence of HIV in order to maximise the reach of these services and the data captured.

It should be noted that the development of IAPT-LTC HIV pathways should not be considered a substitute for the commissioning of HIV clinical psychology services or voluntary sector HIV

support services. These services cater to people with complex or highly specific needs that cannot be addressed by the IAPT-LTC model. Rather, as is discussed in [section 3.3](#), IAPT-LTC HIV pathways should act as one component of a mixed mental health service economy.

#### Recommendations:

- HIV to be added to the list of core conditions covered by the IAPT for Long-Term Conditions (IAPT-LTC) model, enabling IAPT-LTC services to develop specific HIV pathways and ensuring that services are better integrated with HIV treatment and care.
- NHS England and Health Education England to add specific training on the provision of psychological support to people living with HIV to the national curriculum for IAPT-LTC staff. Development of this training should draw on the Standards for psychological support for adults living with HIV and involve consultation with the British Psychological Society, British HIV Association, and Medical Foundation for AIDS and Sexual Health.
- Analysis to be conducted of the potential impact of developing HIV pathways within IAPT-LTC. This could be via an evaluation of pilot services in areas with a high or extremely high prevalence of HIV.

### 4.3 Linking IAPT to a wider system of care and support

The commissioning of mental health support for people living with HIV is complex. Not only is HIV care split between local authorities, NHS England and Clinical Commissioning Groups (CCGs), the commissioning of mental health is also fragmented.

CCGs are responsible for commissioning a large part of the mental health budget within primary care, including IAPT. Secondary care for HIV (i.e. treatment and care provided by HIV clinics) and for mental health (i.e. community, acute and crisis care) is commissioned by NHS England. Since 2013, local authorities hold the public health budget and therefore some of the commissioning for HIV testing and important related services to wellbeing sit within their remit, for example drug and alcohol treatment services.

Fragmented healthcare increases the risk of people falling through the cracks between different services and can result in fewer services

being commissioned as responsibilities are disputed. One of the key concerns raised by our Advisory Group was that there is a pool of people living with HIV whose needs are too complex for IAPT but not complex enough for specialist/secondary mental health care, and therefore have no recourse to NHS support.



**“following the 4 week PTSD group [delivered through IAPT], I was referred to secondary care and waited a year for just the assessment. Since assessment no therapy has been provided”**

**Survey respondent**

Concern about the gap between these service levels is not unique to HIV. A 2020 report by The King’s Fund and Centre for Mental Health, *Mental health and primary care networks*, found that “significant numbers of people in England are falling into a gap between Improving Access to Psychological Therapies (IAPT) services<sup>21</sup> and specialist mental health services.” In other words, people experiencing depression or anxiety disorders alongside other issues, such as co-morbidities around drug and alcohol use, find that local IAPT services are unable to offer them support due to the level of need and complexity involved. At the same time, their referrals are also

rejected by secondary care on the basis that their condition is not ‘severe’ or high-risk enough to meet the thresholds of these services.

People living with HIV are at increased risk of this due to the mental health complexities commonly experienced by this cohort. As the British Psychological Society said in evidence to the APPG on HIV & AIDS, “IAPT uses a CBT framework, which may not be suitable for the complex and longstanding issues that are often observed within the HIV population.” In this context, rising thresholds for accessing specialist mental health services can result in a worrying gap in provision. Several respondents to our survey reported that they had not been able to access any talking therapies on the NHS at all.

While the following sections will outline how IAPT can best support wider mental health pathways for people living with HIV, it is important to recognise that changes to IAPT alone are not sufficient to address gaps in provision outlined above. Greater provision of psychological support within clinical HIV services is required, as is increased implementation of BHIVA Standards of Care and Monitoring Guidelines pertaining to the mental health needs of people living with HIV.<sup>22</sup> This includes ensuring that all HIV services regularly screen patients for mental health problems and have clear referral pathways into mental healthcare.

**Fragmented healthcare increases the risk of people falling through the cracks between different services and can result in fewer services being commissioned as responsibilities are disputed.**

<sup>21</sup> The King’s Fund and Centre for Mental Health, 2020, *Mental health and primary care networks Understanding the opportunities* [<https://www.kingsfund.org.uk/publications/mental-health-primary-care-networks>]

<sup>22</sup> BHIVA, 2018, *Standards of Care*, op. cit; BHIVA, 2019, ‘BHIVA guidelines for the routine investigation and monitoring of adult HIV-1-positive individuals (2019 Interim Update)’ [<https://www.bhiva.org/file/DqZbRxfzlyLq/Monitoring-Guidelines.pdf>]



To support this, we recommend that all HIV services include a psychologist/mental health professional on their multi-disciplinary team (MDT). NHS England should also assess whether provision of psychological support should form a part of the national service specification for HIV services given the high prevalence of mental health need among people living with HIV, and the Department of Health and Social Care should consider mental health within its upcoming HIV action plan.



**“The Department of Health and Social Care should provide clarity on where commissioning and funding responsibilities for HIV mental health and peer support services sit, review funding and show leadership to improve service levels and user experience for people living with HIV.”**

**HIV Commission**

#### Recommendations:

- All HIV clinics should include a psychologist/mental health professional on their multi-disciplinary team (MDT).
- Increased implementation of the BHIVA Standards of Care and Monitoring Guidelines is needed across HIV services in the UK, ensuring that more HIV services are regularly assessing mental health needs among patients, that all HIV services have clear referral pathways into mental health care, and that more HIV services have a designated clinical lead for psychological support.
- NHS England should assess whether provision of psychological support should form a part of the national service specification for HIV services given the high prevalence of mental health issues among people living with HIV.
- The Department of Health and Social Care should ensure that improvements to mental health provision for people living with HIV is included in the upcoming HIV Action Plan.
- Integrated Care Systems (ICSs) should ensure collaboration between all bodies commissioning mental health services within their footprint, so that comprehensive pathways for the full range of mental health support are available for people living with HIV, whatever their particular needs.

### 4.3.1 Ensuring there is stepped-care and clear referral pathways

IAPT is not a mental health panacea and cannot fill gaps that it is not designed to. However, by ensuring that it is well connected to the wider mental and physical health system it can help to minimise them.

IAPT utilises a ‘stepped-care’ model whereby people are offered different types/intensities of treatment according to the severity of their needs. In theory the model works according to the principle that people should be offered the least intrusive intervention appropriate for their needs first, and should then be stepped up or down (or out) depending on their level of progress and need. In practice, we heard that people should often be stepped up sooner or referred to specialist services.

To meet these needs the BPS Standards for the Psychological Support proposes a stepped-care model comprising of four levels of support from Level 1, the most generic, to Level 4, the most specialised. This model should be used to inform the development of mental healthcare pathways for people living with HIV.

Where someone living with HIV has significant but uncomplicated depression or anxiety that is not related to living with HIV, generic IAPT should be equipped to provide support. However, where someone living with HIV has significant but uncomplicated depression or anxiety that is related to living with HIV, HIV-specific support may be required. This is where an HIV pathway within IAPT-LTC could add significant value, alongside voluntary sector HIV support services and clinical HIV psychology services.

Where someone living with HIV has significant psychological problems that are related to HIV and/or in the context of multiple complexities like substance abuse, complex trauma or psychosexual problems, IAPT (generic or otherwise) will not be appropriate. In these circumstances, specialist interventions provided by other services will be required. Such services should include clinical psychology teams within HIV clinics, psychiatric care (both specialist or generic), voluntary sector HIV support services, and drug and alcohol services as appropriate.

To provide fully effective care and support IAPT needs to be connected to these other services as part of the wider health system. At present this does not seem to be the case. Few of the mental health professionals based in HIV clinics that we spoke to reported the existence of referral pathways between their services and IAPT; instead, there was frustration at the lack of

communication between services and concerns about what was happening to people living with HIV who were rejected by IAPT services on the basis of their needs being too complex.

Related to this, both mental health specialists and people living with HIV raised concerns about a lack of clarity regarding inclusion and exclusion criteria for accessing IAPT services. For example, IAPT guidance makes clear that while IAPT is not suitable for people whose primary problem is drug and alcohol misuse, drug and alcohol misuse are not automatic exclusion criteria. Indeed, IAPT have produced a *Positive Practice Guide for working with people who use drugs and alcohol*.<sup>24</sup> Yet a quick online search demonstrates that in practice drug or alcohol misuse is often listed under services' exclusion criteria, and this was a common perception among interview participants. Similarly, while IAPT is not suitable for people who are currently in crisis, we heard from at least one person whose referral was rejected on the basis of historic suicidal ideation despite presenting with moderate needs. If these examples reflect the national picture, there is real cause for concern that a lack of clarity and consistency regarding eligibility criteria could be acting as a significant barrier to accessing help.



**“As soon as someone has drug and alcohol problems, or suicide risk, or a personality problem, IAPT won't see them. These people get seen by in-clinic psychological support if it's available, but it isn't always and their local community mental health care teams might not take them because they have crude exclusion/inclusion criteria. So you have people who are too complex for primary care, but not complex enough for secondary care.”**

**Clinical psychologist**

To prevent people from falling through cracks in the system we recommend that IAPT services develop clear referral pathways with relevant physical and mental health services for people living with HIV. Local pathway documentation can be used to support this process and we would encourage IAPT services to consult directly with relevant services and commissioners. We also recommend that services review and clarify their eligibility criteria and ensure that they are in line with that set out in the IAPT Manual.

### Recommendations:

- IAPT services must develop clear referral pathways with relevant services including clinical HIV services, clinical/health psychology and liaison psychiatry teams, voluntary sector HIV support services, and drug and alcohol services.
- IAPT services to review and clarify their eligibility criteria to ensure that patients who could benefit from support are not unreasonably excluded or deterred from accessing it.

### 4.3.2 A greater role for peer support

Voluntary sector HIV support services are a lifeline to many people with HIV, providing specialist support and advice and connecting people living with HIV to share experiences and build resilience.

One of the key provisions of many HIV support services is peer support. Although peer support is delivered by trained staff or volunteers (living with HIV), participants see each other as equal partners and there is a focus on mutual learning and growth. This can improve people's knowledge, skills and confidence to manage their well-being and overall quality of life.<sup>25</sup> Support can take various forms and address a variety of needs, including emotional (psychosocial) needs.

The value of peer support is widely recognised by medical professionals and people living with HIV, and there is compelling evidence of its effectiveness. *The Standards for psychological support for adults living with HIV* recognise a variety of benefits of peer support, including addressing problems of isolation and facilitating access to further psychological support.

Appetite for peer-delivered mental health support among people living with HIV was demonstrated by the findings of our survey, in which three quarters of respondents strongly agreed (42%) or agreed (33%) that they would like to be able to receive therapy from/with other people living with HIV. The significance of peer support was also a common theme in our interviews. Numerous participants talked about the effectiveness of peer support and the potential impact that accessing it sooner might have had.

<sup>24</sup>Available at: <https://www.uea.ac.uk/documents/746480/2855738/iapt-drug-and-alcohol-positive-practice-guide.pdf>

<sup>25</sup>Positively UK, 2017, National Standards for Peer Support in HIV [[http://hivpeersupport.com/wp-content/uploads/2017/08/national\\_standards\\_final\\_web.pdf](http://hivpeersupport.com/wp-content/uploads/2017/08/national_standards_final_web.pdf)]



“

**“I think if I’d had peer support early on from someone who had been through all of that, and had had help and stuff, I might have listened to them and gone and got therapy earlier when it would have maybe prevented me from getting into the position I got into.”**

**Interview participant**

Many IAPT services offer group therapy sessions which may reproduce some of the benefits of peer support, however the focus of these varies from service to service and we are not aware of any HIV-specific IAPT groups. Some services do offer groups specifically for people with long-term conditions which may help some people living with HIV but is not a substitute for the peer support provided by HIV support services.

“

**“It wasn’t that I didn’t feel comfortable [accessing an IAPT group for people with chronic pain], it’s that I didn’t think their understanding of HIV would be even basic. And the pain that I had, I didn’t have an outward sign that there was something wrong. I didn’t know what was wrong so I couldn’t really explain what it was. I don’t mind sharing my status, that’s not an issue for me, but it would take too much energy to explain what HIV is, and then the focus wouldn’t be on my pain again.”**

**Interview participant**

Several members of the Advisory Group talked about the benefits of people living with HIV receiving peer support alongside wider psychological support and collaboration between peer workers and mental health professionals. Examples of good practice include peer support coordinators joining HIV multi-disciplinary teams. This could perhaps be replicated by inviting peer support coordinators to support local mental health teams or by including both peer support coordinators and IAPT representatives in HIV multi-disciplinary teams.

As a minimum, awareness within IAPT of the value of peer support to people living with HIV is vital, and we recommend the development of clear referral pathways between IAPT services and peer support providers. This depends on the increased commissioning of voluntary sector HIV support services across the country.

#### **Recommendations:**

- Voluntary sector HIV support services should be commissioned in line with need, both to meet needs which generic services are unable to provide appropriately (including peer support), and also to complement, train and work alongside generic provision.

### 4.3.3 Better promotion of IAPT within the wider HIV system

While the focus of this report is on how IAPT services can be improved, a number of people living with HIV highlighted the role that the wider HIV health system can play in supporting access to mental health support services.



**“Services should advertise, I think, through local clinic services like the ones I would access... Each one of us living with HIV generally has to sit in a clinic twice a year to get bloods taken and spend a couple of hours there as it were. Looking at the wall, it wouldn't harm to have few posters just saying, ‘Don't let these things hide.’ I think that would probably be enough.”**

**Interview participant**

While some people living with HIV may never feel comfortable accessing generic services, others are simply unaware of the support available or nervous about approaching services directly. Promotion of these services in healthcare settings which they do feel comfortable accessing can therefore support people to make informed choices about their mental healthcare, as can referrals made by HIV healthcare professionals on patients' behalf.



**“I didn't know it was actually available until my HIV doctor said, ‘We can refer you directly here.’ I didn't actually know that was a thing that they could do, so more signposting on that would be cool”**

**Interview participant**



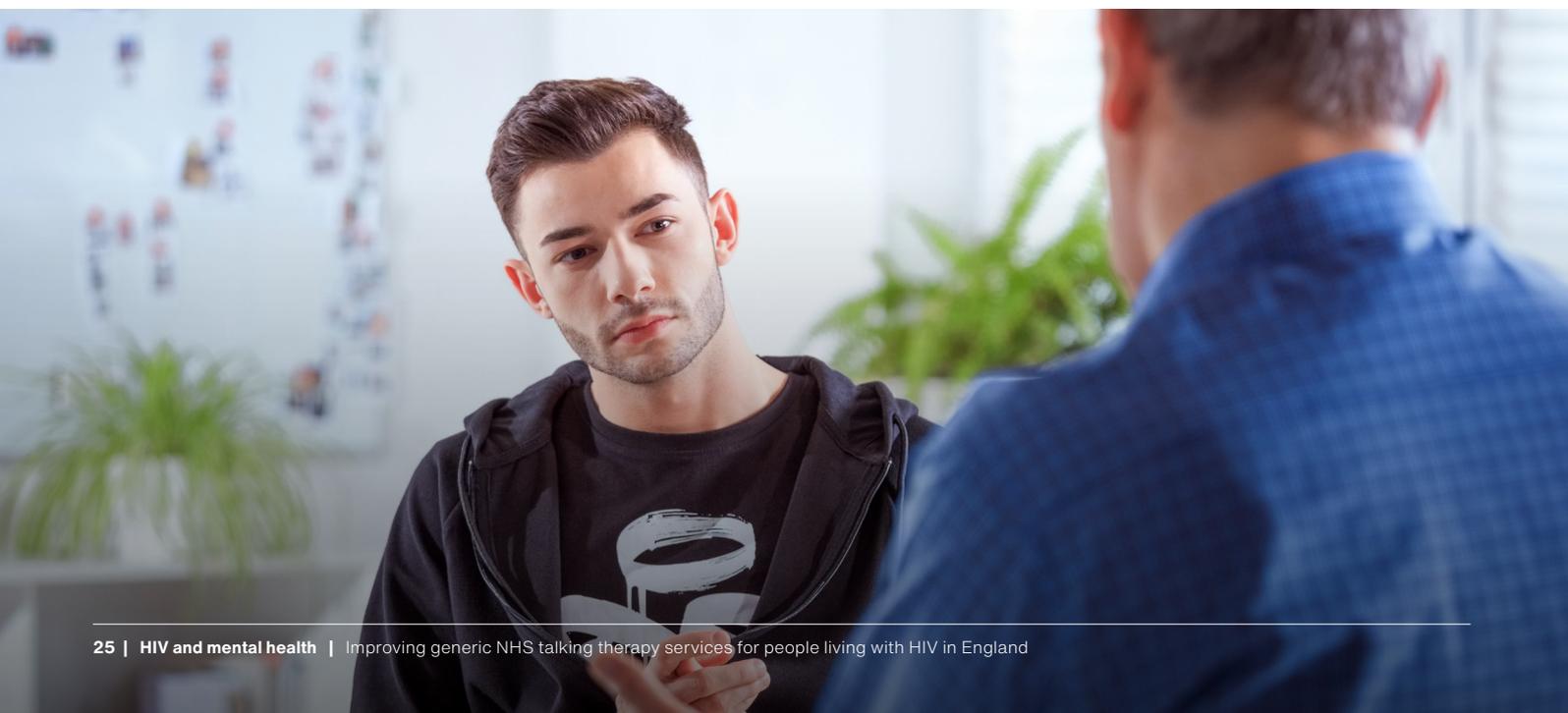
**“IAPT is something I was aware of for a while as something aiming to increase access to psychological therapies, but I didn't really know how to access information about it or the pathways into it.”**

**HIV support service provider**

An obvious barrier to this is the lack of confidence many HIV providers currently have in IAPT, as evidenced by our discussions with clinical and community HIV services. Promoting IAPT more widely is therefore dependent on improvements being made to the IAPT programme via the implementation of the wider recommendations proposed by this report.

#### **Recommendations:**

- IAPT should be better promoted within the HIV system to improve awareness and understanding of talking therapies. Communication about IAPT services should avoid jargon and acronyms and make clear exactly who and how services can help.

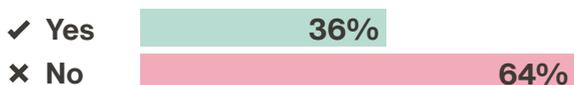


## 4.4 Delivering more person-centred care through IAPT

### i Percentage of survey respondents who were given a choice in each of the following:



### ? Would you have preferred the therapy to have been provided differently in any way?



One of IAPT’s key principles is that treatment should be guided by a patient’s choice, as this has the potential to increase access, enhance engagement, and improve clinical outcomes.



**“When NICE recommends a range of therapies for a particular clinical condition, services should be commissioned so that patients can be offered a choice between the recommended treatments... Patients should also be offered meaningful choices about where, when and by whom therapy should be delivered.”**

IAPT Manual

The findings of our survey demonstrate that in practice choice is incredibly limited, with no more than around a quarter of people given choice in any given element of their care. When we aggregated these elements, we found that just over half (51%) of respondents weren’t offered any choice whatsoever.



**“I wasn’t aware of any choices. It felt very impersonal and like being processed through a therapy conveyor belt. Sessions were very short, for a limited time and of limited benefit.”**

Survey participant

The lack of choice offered is compounded by the finding that over a third of respondents would have preferred their treatment to have been provided differently in some way. When asked to elaborate, people talked about a lack of choice or control over their treatment, feelings of not being heard, and treatment being inflexible and impersonal rather than person-centred.



**“The therapist did what they wanted to do without considering my personal circumstances, my preferred way of doing therapy, my personality. I left therapy worse than when I started.”**

Survey participant

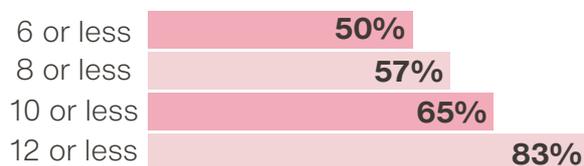
As we saw in [section 3.3](#), among survey respondents CBT and counselling were by far the most commonly prescribed types of therapy. Just 8% of respondents received interpersonal therapy (IPT), 4% received dynamic IPT, and only 2% received eye movement desensitisation and reprocessing (EMDR) therapy. This appears to reflect missed opportunities given the dissatisfaction with CBT expressed by numerous survey and interview participants.



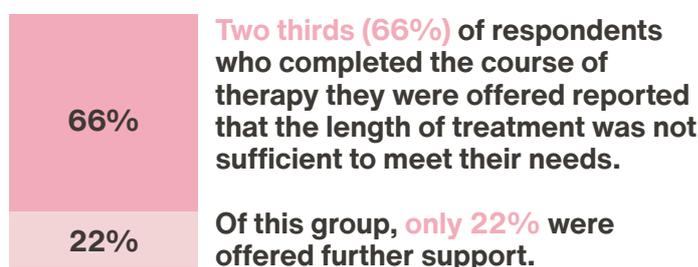
**“that’s part of the reason why CBT didn’t work... we were coming up with coping strategies and I was doing exercises and that sort of thing to cope with the panic, but not any of the other underlying problems. It was treating the most significant or problematic symptom but not any of the causes.”**

Interview participant

### ? How many sessions were offered initially?



### i Length of treatment



With regards to length of treatment, the IAPT Manual recommends:<sup>26</sup>

**“Services are commissioned that can provide the right dose of treatment according to NICE guidelines and do not cap the number of sessions to less than NICE guidelines recommend. Evidence-based treatments should be given at the minimum dose that is necessary to achieve full and sustained recovery. All people being treated should receive an adequate dose of the treatment that is provided. NICE recommends that a person should be offered up to 14 to 20 sessions depending on the presenting problem.”**

While the lengths of treatment reported by survey respondents are not out of line with the national picture of IAPT services, it is clear that for the majority of people living with HIV this is not sufficient to meet their needs, and at present treatment is not meaningfully “guided by the person’s choice.”

Two thirds (66%) of respondents said they felt they needed further support after completing their treatment, yet of them only 22% were offered it. This suggests significant unmet need and a failure on the part of services to identify and refer people onwards appropriately. It may also point to the lack of services available to refer people into following the decommissioning of many HIV support services.

“

**“It takes me a bit of time to open up for a start, to get to know the person so I can trust them. Then there’s time needed to go through the framework issues. I guess for me I take a bit of time to get to the root cause of things and I need longer periods of time with more intensity and that just isn’t available in those services.”**

Interview participant

IAPT services should deliver on the principle of providing meaningful choice to patients by offering greater choice and flexibility as to the way that treatment is delivered. This should coincide with a wider review of IAPT-LTC provision as recommended by National Voices and the Centre for Mental Health in their recent report, *“Ask how I am”*.

“

**“NHS England should review the IAPT Programme for long-term conditions to determine whether its current approach and structure is able to meet people’s needs adequately, how easily accessible it is for people with the full range of long-term conditions, and what modifications may be needed to achieve these aims during the implementation phase of the NHS Long Term Plan.”**

#### Recommendations:

- Greater flexibility as to the types and lengths of treatment provided by IAPT services to be offered to patients living with HIV, in line with the principle of offering patients meaningful choice about their treatment.

**Two thirds (66%) of respondents said they felt they needed further support after completing their treatment, yet of them only 22% were offered it.**

<sup>26</sup>NHS, 2018, The Improving Access to Psychological Therapies Manual, op. cit.



#### 4.4.1 More culturally competent services

In England the populations that are most affected by HIV are men who have sex with men (MSM) and people of Black African ethnicity. Other populations that are disproportionately affected include Black Caribbean communities, people who inject drugs, prisoners, and trans people. These populations are marginalised in other ways such as racism, homophobia and transphobia, and as such are already disproportionately affected by mental health challenges.

Research by Stonewall has demonstrated the higher burden of anxiety and depression on people from LGBT communities, while research from Rethink has equally demonstrated that people from Black and minority ethnic backgrounds are more likely to be diagnosed with mental health problems and less likely to engage with or experience good outcomes from treatment.<sup>27 28</sup>

These communities therefore experience what one member of our Advisory Group described as a ‘perfect storm’ – whereby they face stigma and marginalisation on the basis of both their HIV status and their cultural identity. The impact of this was demonstrated by a recent paper exploring the association between psychological symptoms, socioeconomic factors and ethnicity among older women living with HIV in the UK.<sup>29</sup> Black Caribbean and Black African women were found to be twice as likely to be experiencing social isolation than White British women, and psychological distress was five times more likely among Black Caribbean and three times more likely among Black African women compared to White British women. Despite this, Black African and Black Caribbean women were the least likely to have been diagnosed with depression.

It is important for people providing psychological support to people living with HIV to understand the specific ways that HIV and mental health issues can manifest in different populations, as well as the different cultural attitudes towards them.



**“It is critical to acknowledge that people living with HIV may also be faced with stigma based on other personal demographics that could be acting as compounding factors to their psychological well-being or health behaviours, in particular trans people and people who use drugs.”**

**BHIVA’s Standards of Care for people living with HIV**

The importance that people living with HIV themselves place on cultural competency was demonstrated by the findings of the survey. When presented with the statement “It is important that any therapist I see understands my culture/background/lifestyle”, 51% of respondents indicated that they ‘Strongly Agree’ and 42% indicated that they ‘Agree’. Just 7% reported that that ‘Neither agree nor disagree,’ while no respondents disagreed with the statement.

Evidence of a lack of cultural competency also arose when asking respondents if their therapist had a good understanding of the problems they were experiencing. Just over half of respondents answered either ‘Yes, all of the time’ (20%) or ‘Yes, most of the time’ (28%). Just over a quarter (28%) answered ‘Sometimes, but not always’. 1 in 5 answered either ‘No, not much of the time’ (11%) or ‘No, not at all’ (9%).

Lack of cultural competency around LGBT issues on the part of IAPT providers was also one of the key themes identified in our survey and interviews.



**“when I did open up to [therapy] more, I found it was difficult for the therapist to be on my wavelength. Firstly as a gay man and then secondly as a gay man with HIV. The types of issues surrounding relationships, jobs, family, those things are absolutely coloured by being a gay man and living with HIV. They [the therapist] had not been trained for that, they couldn’t get it... I spent a lot of time explaining to them the background rather than the actual issues. By which time, our sessions ran out. I realise a public health service has to be catering to many, many different needs, but a day’s training on LGBT issues would not go amiss.”**

**Interview participant**

<sup>27</sup> Stonewall, 2018, LGBT in Britain: Health Report [[https://www.stonewall.org.uk/system/files/lgbt\\_in\\_britain\\_health.pdf](https://www.stonewall.org.uk/system/files/lgbt_in_britain_health.pdf)]

<sup>28</sup> Rethink Mental Illness, 2020, ‘Black, Asian and Minority Ethnic (BAME) mental health factsheet’ [<https://www.rethink.org/advice-and-information/living-with-mental-illness/wellbeing-physical-health/black-asian-and-minority-ethnic-mental-health/>]

<sup>29</sup> Solomon D et al., ‘Ethnic inequalities in mental health and socioeconomic status among older women living with HIV: results from the PRIME Study’, Sexually Transmitted Infections doi: 10.1136/sextrans-2020-054788 [<https://sti.bmj.com/content/early/2021/05/05/sextrans-2020-054788>]

Participants also raised issues around race and ethnicity, and the experience of dealing with judgements based on both their identity and their HIV status.



**“it’s about the intersectionality as well. I’m already managing racism and racist perceptions of me without then having to deal with a person’s perspective in terms of HIV. I was too vulnerable to be able to turn around and say, ‘actually, that perception, how you’re treating me or what is inferred or implied’ - I didn’t have the mental capacity or the emotional capacity to challenge it.”**

**Interview participant**

Other participants recognised the experiences of other marginalised groups such as people who inject drugs and sex workers.



**“[therapists] have to understand that HIV’s just a virus and it needs to be managed but that the people who come to them are people who have been affected by not only the virus but by other people’s perceptions of them. So it’s hard enough to be an intravenous drug user, or a sex worker, it’s hard enough to be a gay man because they all have social connotations to them already.”**

**Interview participant**

Data from the IAPT programme itself demonstrates that several groups, including racialised communities, have higher drop-out rates and poorer recovery rates. In our survey, people who identified as Black were less likely to complete therapy than those who identified as White, with only 70% of the former completing therapy compared to 86% of the latter. However, of those who completed therapy, a slightly higher proportion of respondents who identified as Black (60%) reported that their mental health significantly or somewhat improved as result of therapy than those who identified as White (56%).

#### **Recommendations:**

- IAPT staff must be enabled to deliver culturally competent services that reflect the needs of their local populations. This should be supported by the involvement of relevant populations in the design and delivery of services and the provision of staff training on the intersection of mental health with other forms of marginalisation.

#### **4.4.2 A representative IAPT workforce**

It is important that the IAPT workforce is representative of the communities it serves. This is a principle recognised by IAPT itself, which describes a good service as having “A diverse workforce that reflects the local population and is culturally competent.”

For people living with HIV, this does not mean there is an expectation that every IAPT service will be able to offer support from therapists living with HIV. Rather, IAPT services should ensure that the key populations affected by HIV are represented. At present, there are concerns that this is not always the case.



**“For IAPT services to have a better idea of the cohort they serve they need to have a deeper training on and understanding of diversity issues. The current recruitment model favours young graduates that largely come from one demographic – this means that people living with HIV (especially those from BAME<sup>30</sup> communities) don’t feel represented by the service.**

**What our cohort say to us about mainstream services is: ‘the therapist didn’t understand me. They asked me questions that weren’t relevant. I had to explain me before I could talk about the problems I was there for.’ When a client has to continually contextualise their experiences as a Black person, they want to talk about their depression and anxiety but they spend half their counselling sessions putting into context their experience.”**

**BAME-led sexual health agency**

The development of cultural competency can help to mitigate such issues, but representation enables a level of identification that cannot be achieved through cultural competency alone. A number of respondents to our survey reported that their experience would have been improved by receiving support from someone of the same gender and/or ethnicity as them.



**“a good therapist should meet you where you’re at, but if you’re not represented, if there’s nobody who looks or sounds or is anything like you, then you’ve already got a stumbling block before you even get there.”**

**Interview participant**

<sup>30</sup> The acronym BAME is used in this report, but we recognise that people from Black, Asian and Minority Ethnic communities (BAME) are not one homogenous group and we acknowledge that it is not a universally accepted term.

Receiving support from someone of the same identity is not a priority for everyone, and one interview participant highlighted that it can even be a barrier where community stigma is a serious concern. However, what was common among participants was a belief that there should at least be a choice, and that services should strive to be as diverse as possible to enable this.

#### Recommendations:

- IAPT to review staff recruitment policies and actively seek to increase staff diversity and representation.

## 4.5 Improved data collection and reporting

The routine collection of data is a key part of IAPT and something the programme prides itself on, enabling regular monitoring and reporting of clinical outcomes and activity. For people living with HIV, data collection involves particular considerations. The findings of our research also suggest that elements of IAPT's data reporting should be reviewed.

### 4.5.1 Handling personal information and data with care

Everyone in England has the right to confidential medical services. Yet for people living with HIV, confidentiality is especially important. HIV stigma is still pervasive, and Public Health England's Positive Voices survey in 2017 found that 1 in 8 (13%) people living with HIV have not shared their status with anyone outside of healthcare settings.<sup>31</sup> Within healthcare settings, fear or experience of stigma and discrimination is sadly not uncommon, leading to almost 1 in 5 (18%) people living with HIV reporting that they have avoided healthcare when they have needed it.

For people living with HIV to feel comfortable accessing generic health services like IAPT, there needs to be a high level of confidence that their personal information will be kept confidential and a clear understanding of who any information may need be shared with and how. In both regards our findings suggest considerable room for improvement.

While the vast majority (89%) of survey respondents reported that their therapist was aware of their HIV status (either via referral notes or because they told them directly), around 1 in 7 (15%) of them said that they did not feel confident their HIV status would remain confidential. Reasons given included lack of transparency

regarding data sharing, previous experience of mistakes in handling medical records, and broader mistrust regarding NHS confidentiality.



**“I wasn't clear what information was communicated to the first therapist and then in referral on, and to whom any information would be restricted.”**

**Interview participant**

Those interviewed described concerns about accessing services in settings where they may be seen by other people in their community or supported by healthcare workers who may not appreciate the specific confidentiality concerns of people living with HIV.



**“The main barrier [to accessing IAPT for people living with HIV] would be, you don't know whether it's safe to share your status to who you will be talking to. You don't know if you're going to see this person in the street, in the supermarket, or anything like that. You don't know how secure you are, and not all people living with HIV have actually shared that they are positive with their GP in the first place. To then tell a complete stranger or fill in a form online and put that out there on the internet... that's a lot of barriers.”**

**Interview participant**

Participants suggested that services could help to instil confidence before and during the process of referrals by making clear that they are “HIV-friendly,” in the same way that the rainbow flag can be used to provide reassurance to people who identify as LGBT. Others suggested that rather than asking people outright as to whether they have HIV, self-referral forms could ask whether there are any issues that patients would ideally like their therapist to possess knowledge around. This would give people living with HIV the opportunity to highlight their specific needs (e.g. HIV, LGBT issues, etc) and give services the opportunity to identify the most appropriate therapist.

We also heard of concerns about how data is shared between IAPT services and primary care, and whether shared record keeping in services that are co-located means that IAPT records are accessible by GPs. Consent should

<sup>31</sup> Changing Perceptions, 2018, Talking about HIV and Attitudes op. cit.

be sought for information to be shared with GPs (or other healthcare services) where possible, and reassurance provided where it is not. IAPT services should also recognise that the primary point of access to the healthcare system for many people living with HIV is their HIV clinic, so sharing information with HIV clinics (where consent has been provided to do so) may be more appropriate than with GPs. This may be challenging but would help to increase confidence and facilitate more integrated care.

#### Recommendations:

- Data sharing practices and policies should be made clear to patients throughout the IAPT pathway, recognising the particular confidentiality concerns of people living with HIV. This may require reviewing data sharing practices and working with HIV services to enable patients to determine who their records are shared with.

#### 4.5.2 Improved waiting times reporting

The waiting times reported in our survey were significantly longer than those reported by IAPT nationally in 2019-20. Nationally, patients waited on average 22.9 days for their first treatment appointment, and 87.4% of referrals waited less than 6 weeks.<sup>32</sup> In contrast, only half (52%) of respondents to our survey reported being seen within 8 weeks of being referred, and a third waited more than 12 weeks. This discrepancy remained even when only considering respondents who'd accessed IAPT within the last year of reporting, so seems to be a consistent picture.

One possible explanation for this was highlighted by a recent report by the Centre for Mental Health: "contact types [recorded by IAPT services] include assessments such that starting treatment may be conflated with receiving an assessment session." In other words, IAPT's definition of starting treatment may differ from that of survey participants. This is supported by looking at the national data: while 87% of patients had their first appointment within 6 weeks, 33% waited more than six weeks between their first and second appointment, and 19.3% waited more than three months.

Another possible reason for the significant difference in waiting times reported in our survey compared to those reported by IAPT is the way that IAPT calculates this.

At present, data that IAPT publishes on waiting times includes only referrals that finished a course of treatment. In the most recent annual reporting period (2019-20), this eliminated from the data almost half of referrals that started treatment (1.17 million referrals started treatment; 606,192 referrals completed course of treatment). On top of this, more than 500,000 referrals did not start treatment at all.

While there may be pragmatic reasons for measuring waiting times only against referrals that finished a course of treatment, this methodology needs to be reviewed. IAPT should instead assess this indicator against referrals entering treatment (as it did prior to July 2014). This will result in more reliable data that better represents waiting times. We also recommend that IAPT reviews the way services are recording appointment types to ensure that assessment sessions are not being conflated with treatment sessions.

#### Recommendations:

- IAPT should assess waiting times against referrals entering treatment, rather than those completing a course of treatment, and review the way that appointment types are being recorded.

#### 4.5.3 Increased reporting on the equity of outcomes from IAPT

Many of the mental health professionals we spoke to expressed concerns about inequalities in access, activity and outcomes within IAPT. These concerns are not unfounded, and particularly affect populations that are most affected HIV.

NHS Digital produces monthly, quarterly and annual reports on the use of IAPT services, including data on activity and outcomes. The 2019/20 annual report found a range of inequalities: the recovery rate for BAME service users is below that of their White British counterparts, LGB people (outcomes of trans people are not reported on) experience poorer recovery outcomes in IAPT services than their heterosexual counterparts, and people with disabilities and long-term conditions experience worse recovery outcomes than those without.<sup>33</sup> Other inequalities were apparent in relation to economic deprivation, gender and religion.

These inequalities are recognised in the NHS' 2020 Advancing mental health equalities strategy, yet few of the actions identified for

<sup>32,33</sup> NHS Digital, 2020, Psychological Therapies: Annual Report, op. cit.

NHS England and NHS Improvement mention IAPT specifically. Likewise, it is not clear how IAPT services are or will be held accountable for reducing mental health inequalities at the service level. It is possible of course that discussions are ongoing locally to identify inequalities and plan how to address them, but this is not transparent. To instil confidence in services among communities with worse outcomes IAPT services should develop clear action plans for how to address inequalities on at least an annual basis. This should be built into commissioning and plans should be published online.

IAPT reporting should better differentiate between generic IAPT services and IAPT-LTC services. Some indicators (e.g. recovery rates) are already differentiated but this should be expanded to enable fuller assessment and comparison of performance.

In quarterly IAPT reporting HIV is currently subsumed within the variable 'Progressive Conditions and Physical Health (such as HIV, cancer, multiple sclerosis, fits, etc)'. We recommend that HIV is instead added to the list of discrete long-term condition variables so that data can be captured about this cohort specifically. We would also recommend that to support better understanding of mental healthcare inequalities, 'Trans' is added as a gender variable in data collection and reporting.

#### Recommendations:

- IAPT services must develop clear action plans as to how inequalities will be addressed on at least an annual basis. This should be built into commissioning and action plans should be published online.
- Data routinely published by IAPT regarding service activity and outcomes should differentiate between IAPT-LTC and generic IAPT services.
- HIV should be added to the list of discrete long-term conditions that are monitored under the 'Long term conditions' variable in IAPT reporting.
- The experience of trans people accessing IAPT should be monitored by adding 'Trans' as a gender variable in IAPT data collection and reporting.





## 5. Conclusion

### People living with HIV in England are disproportionately affected by mental health problems.

People living with HIV in England are disproportionately affected by mental health problems. This is due to a number of reasons including HIV stigma, the burden of HIV on already marginalised communities, and the challenges of living with a long-term health condition.

While some people living with HIV are able to access HIV-specialist mental health support, some rely on generic mental health services such as IAPT. Funding cuts and the decommissioning of voluntary sector HIV support services in recent years has led some commissioners to suggest that IAPT can competently meet the mental health needs of people living with HIV. In the absence of evidence to back this up, we set out to explore the suitability of IAPT services for this cohort.

The findings of our research demonstrate that while IAPT can be of benefit to some people living with HIV, for many it is not working. 2 in 5 respondents to our survey reported that their mental health did not change as a result of therapy, while 1 in 10 reported that it became worse. Some interview participants described

the provision of support that was simply not appropriate to the level of their needs, and therapists who were not equipped to support them.

For some people living with HIV, IAPT services will never be appropriate due to the complexity of their needs. The retention and increased commissioning of specialist mental health support provided in clinical HIV services and by voluntary sector HIV support services is therefore vital. For others however, improvements to IAPT have the potential to enable more effective support.

A lack of HIV literacy within IAPT services is currently a major barrier. Four fifths of respondents said that their mental health problems were related to living with HIV, yet less than half described their therapist's understanding of HIV as quite or very good, and over a third did not feel their therapist understood the ways in which HIV affects mental health. Perhaps most disappointingly, a large number reported their HIV status negatively affected the way they were treated.

To address this, basic training on HIV and HIV stigma must be added to the national IAPT curriculum. This will help to tackle stigma within IAPT services and ensure that wherever people living with HIV access IAPT they can feel comfortable doing so. To better equip services to meet HIV-specific mental health needs, HIV pathways should be developed within IAPT for long-term condition services and relevant training added to the IAPT-LTC curriculum.

Better connecting IAPT services to the wider physical and mental healthcare system will help to ensure that people living with HIV receive appropriate support and do not fall through cracks in the system. This requires effective stepped-care and the development of clear referral pathways between IAPT, HIV-specialist services and drug and alcohol services.

If IAPT services are to effectively meet the needs of communities affected by HIV, concerns about a lack of cultural competency and representation must be addressed. This should also be supported by improved reporting on and accountability as to inequalities in the activity and outcomes of IAPT services.

Ultimately, people living with HIV in England are a diverse community with a wide range of mental health needs. IAPT cannot be expected to meet all of those needs, but must be as effective as possible in meeting the needs of those who meet its criteria for support as part of a mixed model of mental health provision. Our recommendations provide decision makers with clear steps for how to achieve this, and they must be urgently implemented in order to improve the mental health outcomes of people living with HIV.



# Acknowledgements

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# NATIONAL AIDS TRUST

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**We're the UK's HIV rights charity. We work to stop HIV from standing in the way of health, dignity and equality, and to end new HIV transmissions.**

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