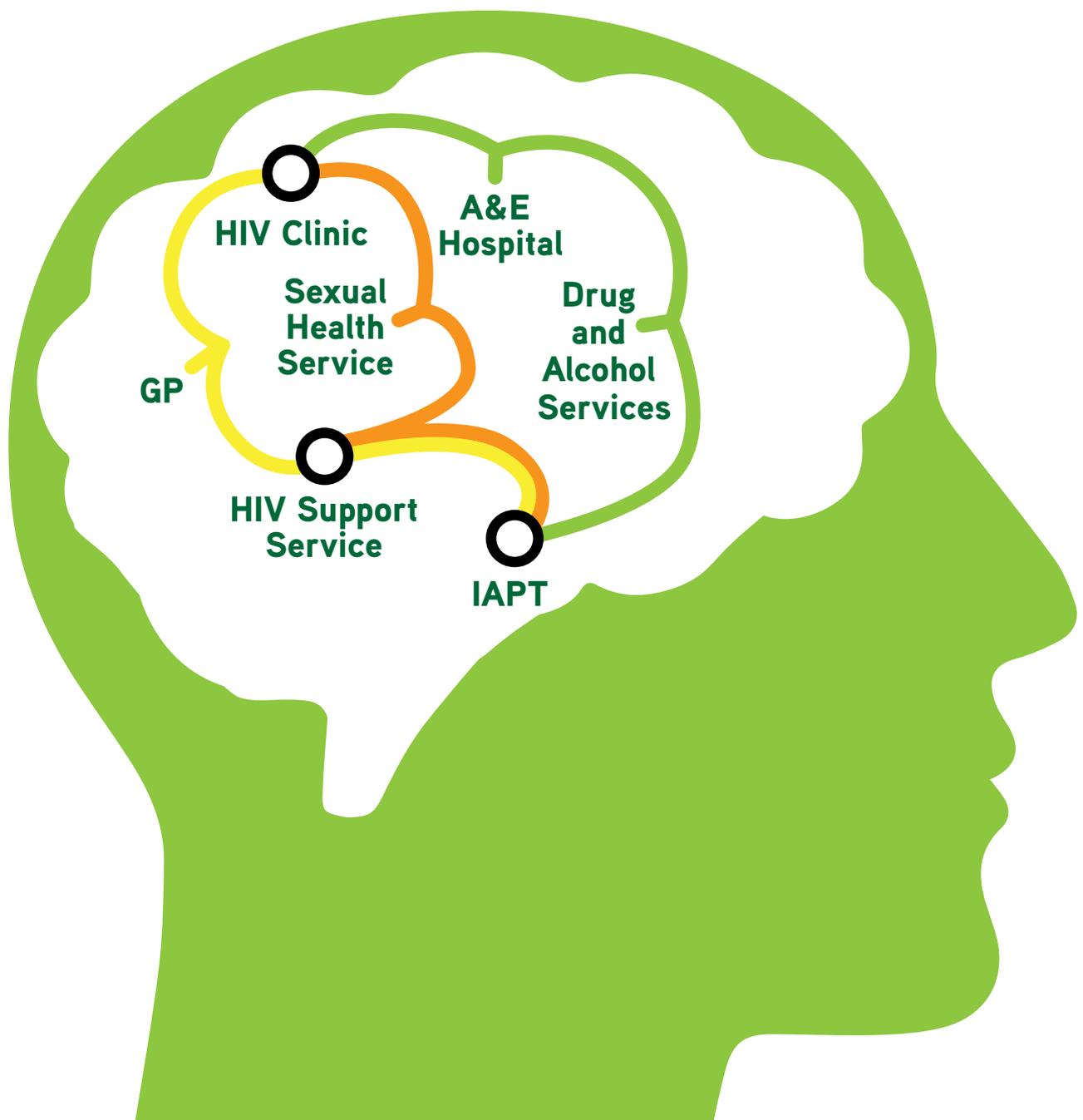


# The Missing Link: HIV and mental health





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# Definitions

**Psychosocial support** – in this report refers to support services which are on the whole, provided by the third sector. It does not include mental health/psychological services provided through the Health Service.

**Psychological/mental health services** – is used interchangeably to describe services provided by the Health service through primary and secondary care. It is used as a generic term to describe all levels of mental health services ranging from mild to severe but does not include psychosocial support which is provided through local authorities. While there may be some crossover in terms of the provision of services across mental health/psychological services provided by primary and secondary care and HIV specific psycho-social support provided by local authorities, for clarity, this report uses these separate definitions.

**Chemsex** – means using drugs as part of your sex life, and it's most common among men who have sex with men. There are typically three specific 'chems' (drugs) involved. People say these drugs make them feel less inhibited and increase pleasure. The three main drugs people take as part of chemsex are methamphetamine, mephedrone and GHB/GBL<sup>1</sup>.

**U=U “Undetectable = Untransmittable”** – When HIV medication suppresses the virus to undetectable levels. That makes you untransmittable. You can't spread the virus sexually.

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1 Change Grow Live website <https://www.changegrowlive.org/advice-info/alcohol-drugs/chemsex-drugs>

## List of abbreviations

<b>APPG</b>	All Party Parliamentary Group
<b>ART</b>	Antiretroviral therapy
<b>BAME</b>	Black Asian and Minority Ethnic
<b>BHIVA</b>	British HIV Association
<b>BASSH</b>	British Association for Sexual Health and HIV
<b>CAT</b>	Cognitive Analytic Therapy
<b>CBT</b>	Cognitive Behaviour Therapy
<b>CCG</b>	Clinical Commissioning Groups
<b>CHIVA</b>	Children's HIV Association
<b>DHSE</b>	Department for Health and Social Care
<b>DWP</b>	Department for work and pensions
<b>EDMR</b>	Eye Movement Desensitisation and Reprocessing
<b>HAND</b>	HIV Associated Neurocognitive Disorder
<b>IAPT</b>	Increased Access to Psychological Therapy
<b>ICS</b>	Integrated Care System
<b>LGBT</b>	Lesbian Gay Bisexual and Transgender
<b>MDTs</b>	Multidisciplinary Teams
<b>MSM</b>	Men who have sex with men
<b>NAT</b>	National AIDS Trust
<b>QoL</b>	Quality of Life
<b>SLAM</b>	South London and Maudsley Trust
<b>RVI</b>	Royal Victoria Infirmary
<b>STP</b>	Sustainable Transformation Projects
<b>THT</b>	Terrence Higgins Trust

# Foreword



Mental health has become an increasing priority for the UK Government as awareness about the impact that poor mental health can have on a person's quality of life is rightly recognised. Equally, poor mental health can affect any one of us and public figures like the Duke of Sussex who have spoken openly

about their own struggles have made huge strides in breaking down the stigma associated with the issue.

HIV is also heavily stigmatised. While treatment in the UK is now so advanced that living with HIV should be like living with any other long-term condition, the sad fact is that HIV stigma has not really moved on since the 1980s when millions of people were dying from AIDS.

We carried out this inquiry because we wanted to look at the impact of having two stigmatised comorbid conditions - mental health and HIV - and whether the health service is set up to deal with the specific challenges that this comorbidity poses. We know that stigma is bad for mental health, but one of the key points raised by this report is that stigma is preventing people from accessing the treatment and care that they need.

Mental health support for people living with HIV does exist but it is becoming mainstreamed because HIV is no longer seen as a life-threatening condition. While the real "threat" of HIV may have disappeared the "perceived" threat continues to exist through stigmatising, outdated attitudes which have a hugely detrimental impact on the effectiveness of treatment and are contributing to the increase in late diagnosis.

Addressing mental health needs is crucial to the HIV response and our success in reaching the 2030 target of zero new infections. It has been a privilege to serve as Chair of the APPG on HIV and AIDS for the past two years and I am committed to ensuring that the next few years will see an increased focus on mental health and HIV as the "missing link" to finally end the HIV epidemic once and for all.

**Stephen Doughty MP**  
Chair of the All Party  
Parliamentary Group on HIV/AIDS

# Acknowledgements

Thank you to all of the stakeholders who have worked with us throughout the course of the inquiry. Particular thanks go to the multidisciplinary team at the RVI in Newcastle and the Blue Sky Trust for facilitating a visit to meet their service users. Thankyou to all of our witnesses who attended the oral evidence sessions, in particular those who provided additional support with the report including Chris Hicks from National AIDS Trust (NAT), Dr Ben Spencer from the South London and Maudsley Trust, Dr Amanda Williams CHIVA Chair, Dr Kate O'Reilly from the Royal Victoria Infirmary (RVI) and Terrence Higgins Trust (THT). This report was compiled by Susie Pelly, Senior Policy Advisor to the APPG on HIV and AIDS. If you would like further copies please contact [pellys@parliament.uk](mailto:pellys@parliament.uk).

# Foreword

Stigma ruins lives. It can make us feel isolated, ashamed and worthless. It can stop us from building relationships or accessing work. It can prevent us from seeking help or treatment. It can deny us the opportunity to live our lives to the full.

A decade ago mental health did not have anything like the profile it has now. Thanks to campaigns like Time to Change and the growing numbers of people who have had the courage to speak out about mental health, we are starting to see an improvement in attitudes towards those of us with mental health problems. But there is still a long way to go, particularly for those of us who may be experiencing stigma for other reasons too.

As this report demonstrates, stigma continues to have a pervasive impact on the lives of people living with HIV, many of whom will also have a mental health problem. It's hard enough to be living with a long-term health condition and experiencing a mental health problem, without having to face the judgement, shame and isolation that often surround them. Therefore, as Mind, we welcome the APPG's focus on trying to understand the experiences of people living with both HIV and mental health problems.

For too long those of us with mental health problems have had to put up with second-rate, second-class services. While there has been some welcome progress in recent years, too many of us still struggle to access support for our mental health and, as this report highlights, this is often the case for people living with HIV. People living with HIV are twice as likely as the general population to experience a mental health problem. However, support for people living with HIV has continued to focus on clinical treatment, with significant numbers of HIV Clinics not even having access to mental health professionals in their Multi-Disciplinary Teams. We cannot continue to treat physical and mental health in siloes and we welcome the APPG's recommendation for an integrated care pathway to ensure mental health services are accessible for people living with HIV.

It's also encouraging to see the APPG looking at issues outside of health services and particularly the impact of the benefits system. Our mental health is affected by a huge range of factors - the quality and security of our homes, employment status and money worries, transitions between school, university and beyond, to name but a few. There is limited value in the UK Government putting money into health services to help people when they are unwell if, at the same time, it undermines mental health through a flawed benefits system. Politicians from all parties have begun to understand this point in recent years, but we now need to see decisive action.

To truly transform the lives of people living with HIV and mental health problems, the UK Government must recognise the connections between our physical and mental health as well as the wider social factors that impact on our mental health. It is only by developing a cross-government approach to mental health will we be able to really improve the experiences of people with mental health problems and we hope this report goes some way towards helping to make that case.

**Paul Farmer CBE**  
Chief Executive of Mind

# Foreword

## The Psychosocial Network

There have been remarkable advances in HIV treatment, prevention and care in the UK. Most people on HIV treatment have normal life expectancy, and live with the knowledge that they cannot transmit HIV. Rates of new infections are falling. Yet while there is much to celebrate, people living with HIV are still twice as likely to experience poor mental health as the general population.

This report by the All-Party Parliamentary Group on HIV makes a valuable contribution to the discussion on HIV and mental health. It highlights the extent and seriousness of mental health difficulties, and reasons for them, such as poor physical health's effects on mental health, stressful benefits cuts, and widespread stigma which prevents people accessing help and engenders isolation and loneliness.

As treatments have improved and funding cuts increased, psychosocial support for people living with HIV has been mainstreamed or cut. Policymakers, healthcare practitioners and service commissioners often treat HIV as simply a manageable long-term condition, failing to tackle the trauma of diagnosis and the extent of poor mental health amongst people with HIV. Unless these failures are addressed, medical success in tackling the epidemic will be a hollow victory.

The report documents current difficulties of meeting HIV-related mental health needs within stretched, fragmented medical services, overextended mental health services, and defunded and shrinking local HIV organisations on which many people rely for help with mental health.

As a group of activists, service providers, and researchers, the HIV Psychosocial Network welcomes this report's recommendations. There is a clear need for new government strategies to support, in an integrated, sustainable way, the mental health and well-being of people with HIV, while recognising the complexities of HIV experiences and the specific needs of different groups.

The report brings together a wealth of experience and evidence about HIV and mental health, including the voices of people living with HIV. It has the potential to inform and educate decision-makers, practitioners and the wider population about why people with HIV need specialist and general mental health provision, and why their needs vary. More broadly, it presents an opportunity to rethink the psychological and social health systems of the future – an initiative which the HIV Psychosocial Network fully supports.

**Tomas Campbell, Drew Dalton, Peter Fleming, Guillermo Llorca, Sanny Mulubale, Mel Rattue, Fraser Serle and Corinne Squire, for the HIV Psychosocial Network.**

# Executive Summary

The UK is a world leader in terms of clinical treatment of HIV, with 98% of people on treatment and 97% virally suppressed. Despite these successes, the response to stigma in the UK significantly lags behind the gains we have made in prevention, testing and treatment. Both 'actual' and 'perceived' stigma around HIV are still very much alive and severely impact on a person's well-being and mental health and in extreme cases have even resulted in suicide. Benefit reviews are reportedly one of the key triggers for suicides amongst people with HIV, due to the significant distress caused by the review process on an already vulnerable population.

People with HIV are twice as likely to experience mental health issues compared to the general population.<sup>2</sup> In Positive Voices, 50% of people with HIV reported feelings of depression or anxiety on any given day (compared to 24% of the general population).<sup>3</sup> Despite this increased incidence of mental health conditions for people with HIV, treatment remains largely focused on the clinical side of HIV.

Mental health and HIV are acutely related for a number of interrelated reasons. People with HIV are more likely to have mental health problems and people with mental health issues are more likely to acquire HIV. Mental health and HIV disproportionately impact the same groups of people who are marginalised and suffer from socio-economic deprivation such as the Lesbian, Gay, Bisexual, Transgender (LGBT) and Black, Asian, Minority Ethnic (BAME) communities. Chemsex, HIV and mental health are also closely associated. Chemsex drug use is a growing issue among men who have sex with men (MSM) living with HIV and these men report frequent mental health symptoms<sup>4</sup>. Chemsex is also frequently reported in MSM who are at higher risk for HIV acquisition. The use of chemsex drugs may be a way of dealing with a previously existing mental health condition, an HIV diagnosis or can directly cause mental health issues because of the chemical effects of the drugs. 47% of chemsex users report having an HIV diagnosis.<sup>5,6</sup>

Mental health issues should be given parity of esteem with HIV clinical treatment. Since the Health and Social Care Act 2012 there has been a decrease in the level of psychosocial support available to people with HIV in England because support services often fall through a gap in commissioning as they have no specified commissioning home. Cuts have caused some services to reduce their provision and in some cases services have been fully decommissioned. While mental health services for the general population are receiving greater investment through the government's commitment to parity of esteem between physical and mental health, these services are not always equipped to deal with the very specific mental health issues around HIV and stigma and are not currently fit for purpose.

2 NAT Website, Positive Voices Survey 2018, 'Changing Perceptions: Talking about HIV and our needs' [https://www.nat.org.uk/sites/default/files/publications/web\\_PV\\_Changing%20Perceptions-needs-report.pdf](https://www.nat.org.uk/sites/default/files/publications/web_PV_Changing%20Perceptions-needs-report.pdf)

3 Ibid.

4 Pufall, E. L., Kall, et al. (2018). Sexualized drug use ('chemsex') and high-risk sexual behaviours in HIV-positive men who have sex with men. *HIV medicine*, 19(4), 261-270.

5 London Friend, oral evidence

6 McCormack S, Dunn DT, Desai M, et al. Pre-exposure prophylaxis to prevent the acquisition of HIV-1 infection (PROUD): effectiveness results from the pilot phase of a pragmatic open-label randomised trial. *Lancet*. 2016;387(10013):53-60.

The commissioning landscape for HIV and mental health is extremely complex (in England) because they are two separate conditions with separate commissioning arrangements and care pathways. Somebody with a pre-existing mental health condition can acquire HIV and equally somebody with HIV can develop a mental health illness, therefore ensuring that mental health and HIV is commissioned in a more integrated way is a significant challenge. Mental health support for people living with HIV is split into four different levels and the amount of support available depends on the level of need. At the more severe end of the spectrum there is better support available through HIV clinics however this is not necessarily the case throughout the whole country with nearly 40% of HIV clinics reporting that they have no psychological or mental health support within the clinic. The main gaps in provision are around less severe mental health conditions where people with HIV are expected to use generic mental health services where mental health professionals are not necessarily trained in HIV and the impact that stigma can have a person's mental health. Lack of HIV specialism within generic mental health services acts as a real deterrent for vulnerable people to access the help they need. In order to avoid people reaching crisis point it is vital that the government invests resources for all levels of mental health need.

In order to treat HIV effectively it is necessary to address any comorbid mental health conditions as these can affect adherence to medication and overall health outcomes. There is a clear public health incentive for investing in mental health services for people living with HIV. Failure to adhere to medication means you are more likely to pass on the virus because when you are undetectable you are untransmittable. The lack of psychological support within HIV clinics is therefore a major barrier to effectively treating HIV and reaching the 2030 target of zero new infections.

Cognitive impairment is one of the most worrying issues which psychiatric clinicians face today. While cognitive impairment is a medical condition which affects many people and is not restricted to people living with HIV, in HIV, cognitive impairment can be as a result of the direct impact of infection in the brain. The increased likelihood of cognitive impairment in people with HIV and the difficulty in diagnosing HIV Associated Neurocognitive Disorder (HAND) are further evidence of the need for specialised HIV psychiatry/ psychology.

There are a variety of issues in children and young people that contribute to poor mental health. These include HIV stigma, bereavement, secrecy, migration, child caring roles and social isolation. Children born with HIV are also more vulnerable to cognitive impairment issues as a consequence of living with HIV and not necessarily taking effective treatment throughout the course of their lifetime.

As a consequence, specific mental health issues such as anxiety, depression and psychosis may arise in older children and adolescents. Psychological support for children and families living with HIV is needed to promote good mental health within childhood and later life.

While not everyone living with HIV will suffer from mental health issues within their lifetime, there is clear evidence to show that mental health and HIV are closely interrelated and that in order to treat HIV effectively you cannot ignore a person's mental health. Late diagnosis is increasing – from 42% in 2016<sup>7</sup> to 43% in 2017<sup>8</sup> – in part, because of the fear of receiving an HIV diagnosis. Late diagnosis and lack of adherence to HIV medication are both linked to stigma and ultimately have the same

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7 Public Health England 'Towards elimination of HIV transmission. AIDS and HIV-related deaths in the UK 2017 report', November 2017

8 Public Health England 'Progress towards ending the HIV epidemic in the United Kingdom 2018 report' November 2018

effect - the longer people are left undiagnosed or not on effective treatment, the more likely they are to pass on the virus. The links between HIV stigma, mental health, and late diagnosis need to be made across the health system if we are going to meet the 2030 zero new infections target.

**OUR KEY FINDINGS ARE:**

- People living with HIV are twice as likely as the general population to have a mental health illness in their life-time but nearly 40% of HIV clinics do not have access to a psychological or mental health professional within their multidisciplinary teams (MDTs).
- Mental health support is proven to increase adherence to HIV medication by 83% in people with depression. Despite the clear public health benefits to treating mental health issues in people with HIV, it is generally not until people reach the more severe end of the mental health spectrum that specialised HIV services are provided.
- In the past HIV support services have provided psycho-social support for people who are newly diagnosed or struggling to cope with their HIV diagnosis. Many of these services have been decommissioned leaving people no choice but to access generic services for their mental health needs associated with their HIV diagnosis. There is no evidence that these services are effective for people with HIV and the APPG is concerned that in their current form, they are not fit for purpose.
- Young people who have acquired HIV from birth are particularly vulnerable to mental health crises for a number of reasons and there is great concern that as adolescents are moved into adult services where there is less specialised care, they are at a trigger point for a mental health crisis.
- Benefit reviews are leading to suicides in people with HIV as a direct result of assessors not understanding the psychological effects of stigma, mental health issues and HIV.
- People with chemsex addiction are falling through commissioning gaps as drug and alcohol services are commissioned by local authorities but do not necessarily treat specific chemsex drugs or associated mental health issues and mental health services are commissioned by Clinical Commissioning Groups (CCGs) but do not provide addiction services.

# Methodology

The APPG put out a call for written evidence in February 2019 and we received around thirteen submissions as well as more personal representations from individuals living with HIV. In May, June and July we carried out three oral evidence sessions including the main HIV and mental health organisations, Public Health England and a number of psychology and psychiatry professionals from across a range of hospital trusts in England – from Manchester, Newcastle and London. This inquiry deals with HIV policy that relates specifically to England given that health is devolved in Scotland, Wales and Northern Ireland.

In July the APPG visited an HIV support service in Newcastle and met with the multidisciplinary team at the Royal Victoria Infirmary in Newcastle. This session provided an additional evidence base to inform the findings of this inquiry. The final report is a combination of literature review on the impact of HIV and mental health which is well documented and personal and professional testimonies from a wide range of professionals working in HIV and mental health as well as people living with HIV and mental health problems.

While the report recognises that different groups of people living with HIV live differently with HIV and have different needs -- for instance, long-term survivors, the newly diagnosed, diverse BME groups, heterosexual, gay and bisexual men, women, trans people, older people, children and young people, people who use drugs and formerly used drugs, people from diverse religious backgrounds, refugees and asylum-seekers, and the many people with HIV who have experienced trauma - we use examples which we encountered from our research which do not necessarily reflect the full spectrum of communities within the broader group of people living with HIV in the UK. The reflections and recommendations however apply to all people living with HIV.

# Recommendations

## The Department for Health and Social Care:

1. A comprehensive strategy for reducing HIV stigma in the UK is urgently needed. The response to stigma in the UK significantly lags behind the gains we have made in prevention, testing and treatment. As a first step, there should be an overarching campaign to reduce stigma across the NHS.
2. BAME communities should be included in the design and implementation of any strategy to reduce stigma given the high prevalence of HIV within BAME communities and specific cultural attitudes and norms that affect treatment adherence and can increase levels of stigma.
3. “Perceived stigma” is a mental health issue which requires different interventions. People with HIV who are afraid to access mainstream services because of perceived stigma need to be able access HIV specific services or health professionals who are trained in HIV stigma and its impact on mental health. The Department for Health and Social Care (DHSC) need to ensure there is a clear commissioning pathway or service specification to make this possible.
4. HIV support services are a crucial part of the care pathway and should have a clear commissioning home.

## NHS England:

1. The NHS England HIV service specification should recognise the impact of stigma on mental health and adherence to treatment and include mental health support as part of the core service.
2. Mental health support for children and young people with HIV should also form part of the service specification and have the same weighting as clinical treatment.
3. Sustainable Transformation Partnerships (STPs) should be assessing how improvements on the integration between physical and mental health services can be made.
4. STPs, especially those in high prevalence areas, should be considering HIV-related issues as part of the development of their new five-year plans and their ongoing workplan.
5. NHS England should be considering how STPs/Integrated Care Systems (ICS) can ensure integration of and improvements in mental health and HIV.
6. Local HIV stakeholders should take the initiative in developing proposals for STP consideration and persist in advocating for them.
7. NHS England should assess whether provision of psychological/mental health support should form a part of the national service specification for HIV services given the high prevalence of mental health issues amongst people with HIV. This could help overcome any commissioning barriers to the provision of mental health services.
8. NHS England should assess the HIV competency of all Increased Access to Psychological Therapy (IAPT) services. This could form part of NHS England’s ongoing work to improve IAPT services for people with long-term conditions.
9. Generic services should never be proposed as an acceptable alternative to HIV-specific services when those generic services are under-resourced, failing to meet demand appropriately even without HIV positive service users, and where staff of such services have not been meaningfully and effectively trained on HIV issues.

10. Psychological support is needed for paediatric and young people's services to allow early identification of neurocognitive difficulties and family focussed support through to transition into adult services.

### **Local Authorities and Public Health England:**

1. Chemsex should be looked at holistically alongside HIV and mental health and this should be taken into consideration when commissioning services.
2. Chemsex services should be available at sexual health clinics and HIV clinics

### **The Department for Work and Pensions (DWP):**

1. The DWP must look again at Personal Independence Payment and whether the assessment design, criteria and current approach to scoring are suitable for a benefit designed to promote participation and independence.
2. The welfare system should be sensitive to the impact of an HIV diagnosis. This could be achieved by integrating HIV-related topics and their impact on mental health into the training of assessors. There also needs to be explicit attention paid to issues around confidentiality and HIV, which takes into account the possibility that people may not disclose their HIV status due to concerns relating to stigma and discrimination.
3. It is particularly important for assessors to understand the power of stigma and trauma and their potential to impact a person's ability to function on many levels. Assessors for welfare benefits should also be aware of the potential iatrogenic effects of the assessment process and pay attention to their own language and communication, which may also result in service user distress.

### **HIV Clinics and commissioners:**

1. Increased implementation of the BHIVA Standards of Care and Monitoring Guidelines are needed across HIV services in the UK, ensuring that more HIV services are assessing mental health needs amongst patients, ensuring 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.
2. All HIV services should be assessing how to offer psychological support within the HIV service. Given the prevalence of mental health problems amongst people with HIV and the need to overcome fragmentation and barriers to mental health services within the healthcare system, HIV clinics offer an ideal setting to provide psychological support.
3. All HIV clinics should include a psychologist on their MDT and access to a psychiatrist with HIV expertise.

### **The Department for Education:**

1. School/university counselling services need to have basic HIV awareness training or at least be able to signpost to the local HIV support service.

# Introduction

There is no doubt that living with HIV in the UK means that you will have access to gold standard clinical treatment. Compared to other parts of the world where AIDS continues to be the biggest killer of women of reproductive age<sup>9</sup>, out the UK's 101,600 people living with HIV, 98% are on treatment and 97% are virally suppressed.<sup>10</sup> We have already reached the 90:90:90 goals for 2020. Despite this progress in treatment, HIV stigma remains an insidious part of many people's lives.

Where it exists, stigma can permeate a person's core beliefs and affect their overall 'quality of life' (QoL). As highlighted in the recent Positive Voices survey conducted in collaboration with Public Health England the overall utility score for quality of life (EQ-5D index) of people with HIV in the UK was 0.604, compared to 0.856 in the general population of England (see figure 1 below for a more detailed picture).<sup>11,12</sup> QoL for people with HIV has become increasingly important in policy discussions about the future of HIV treatment and care both within the UK and internationally. While the global commitments on HIV such as the Sustainable Development Goals and the 90:90:90 UNAIDS targets to do not reference QoL, there is an ever-increasing consensus that QoL should be specifically integrated into a country's HIV response. This consensus has been highlighted in the UK in recent guidance by the British Psychological Society<sup>13</sup> and British HIV Association<sup>14</sup>, and internationally, by work proposing QoL as the 'fourth 90'.<sup>15</sup>

Within the UK, there has been no specific HIV strategy since the last Labour Government. HIV policy is now largely focused on the clinical treatment of HIV. Within England, support services have been one of the main pillars of specialised care for people with HIV. However, as the UK Government has cut funding for local authorities, and CCGs are also in difficult financial positions, support services and mental health services have become severely stretched, and there are questions around the current level of support available for people with HIV within England. This has become particularly acute since the implementation of the Health and Social Care Act in 2013 which has left no clear mandate for the provision of HIV support services, as is outlined in the APPG's report: 'The HIV Puzzle: piecing together HIV care since the Health and Social Care Act'. The negative impact of these changes have also been highlighted in a recent audit by the HIV Psychosocial Network<sup>16</sup>.

9 UNAIDS 2018 [https://www.unaids.org/sites/default/files/media\\_asset/women\\_girls\\_hiv\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/women_girls_hiv_en.pdf)

10 Public Health England Public Health England 'Progress towards ending the HIV epidemic in the United Kingdom 2018 report' November 2018

11 Devlin, N. J., et al. (2017) Valuing health-related quality of life: An EQ-5D-5L value set for England. *Health Economics*. 2018; 27: 7–22.

12 Szende A., et al. (2014) *Self-Reported Population Health: An International Perspective Based on EQ-5D*. Dordrecht: Springer

13 British Psychological Society 'Standards for Psychological Support for Adults Living with HIV 2011, November 2011

14 BHIVA Standards of Care 2018, Standards 2 and 6

15 Lazarus et al., "Beyond viral suppression of HIV – the new quality of life frontier" *BMC Medicine* 14.1 (2016): 94.

16 HIV Psychosocial Network 'After ten years: an 'austerity audit' of services and living conditions for people living with HIV in the UK, a decade after the financial crisis' 2017 <https://hivpsychosocialnetworkuk.files.wordpress.com/2018/11/10-years-after-report-final.pdf>

In the latest Public Health England policy on HIV: 'Health promotion for sexual and reproductive health and HIV: Strategic Action Plan, 2016-2019,<sup>17</sup> mental health and HIV support services are not explored in any detail. The NHS England service specification for adult HIV services does make clear that specialised clinical care needs to be complemented by other provision.<sup>18</sup> The NHS England service specification for children's HIV services stresses the importance of provision of peer support, community and voluntary sector providers and non-specialised HIV care and support, however NHS England does not commission these services.<sup>19</sup>

These changes to the commissioning of HIV and lack of specific focus on the psychosocial aspects of care are leaving a considerable gap because, although HIV treatment has moved on since the 1980s, outdated attitudes and stigma continue to undermine the clinical achievements of the past three decades. Stigma, including self-stigma, is still a major problem for people with HIV. The UK Stigma Index and Positive Voices survey together provide a solid empirical database of the levels of stigma that are experienced by people with HIV. Stigma also continues to exist regarding mental health, and therefore 'double stigma' can occur. Furthermore, mental and physical health are strongly connected; for people with HIV their physical health issues are more likely to cause mental health challenges compared to the general population and mental health issues may have increasingly negative physical effects on people with HIV.

The importance of tackling mental health and HIV in a more integrated way is becoming increasingly evident. According to Public Health England's most recent report on the HIV epidemic in the UK<sup>20</sup>, people living with HIV are twice as likely to have anxiety and depression compared to those who are not living with HIV. Chemsex is becoming a growing public health concern and is closely linked to HIV and mental health with around half of the clients from one of the main providers of chemsex services in the UK reporting that drug use escalated following their HIV positive diagnosis and a third saying their drug use only started following their positive diagnosis<sup>21</sup>.

Different groups of people living with HIV, many of them socially and/or economically marginalised, live differently with HIV and have different needs – for instance, long-term survivors, the newly diagnosed, diverse BME groups, heterosexual, gay and bisexual men, women, transwomen, older people, children and young people, drug users and former drug users, people from diverse religious backgrounds, refugees and asylum-seekers, and the many people with HIV who have experienced trauma. This complexity among people with HIV mirrors society, and also generates specific HIV-related requirements, including around mental health.

Given that the Government has committed to parity of esteem between mental and physical health by 2020 and has recently pledged an annual increase of £20.5 billion for the NHS – now seems a particularly appropriate time to address the links between HIV and mental health. Most recently, HIV was not mentioned within the Department for Health and Social Care 'Long Term Plan' published in January 2019, or in the 'Prevention is better than Cure' paper published in November 2018. Consequently,

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17 Public Health England 'Health promotion for sexual and reproductive health and HIV: Strategic Action Plan, 2016-2019, "In addition to specialised HIV services, meeting the needs of HIV infected individuals relies on access to other services including sexual health and reproductive health, mental health, antenatal and third sector support services." <https://www.england.nhs.uk/wp-content/uploads/2013/06/b06-spec-hiv-serv.pdf>

18 NHS England "NHS STANDARD CONTRACT FOR SPECIALISED HUMAN IMMUNODEFICIENCY VIRUS SERVICES (ADULTS)" <https://www.england.nhs.uk/wp-content/uploads/2013/06/b06-spec-hiv-serv.pdf>

19 NHS England "NHS STANDARD CONTRACT FOR SPECIALISED HUMAN IMMUNODEFICIENCY VIRUS SERVICES (CHILDREN)" <https://www.england.nhs.uk/wp-content/uploads/2013/06/b06-spec-hiv-child.pdf>

20 NAT Website, Positive Voices Survey 2018, 'Changing Perceptions: Talking about HIV and our needs' [https://www.nat.org.uk/sites/default/files/publications/web\\_PV\\_Changing%20Perceptions-needs-report.pdf](https://www.nat.org.uk/sites/default/files/publications/web_PV_Changing%20Perceptions-needs-report.pdf)

21 Monty Moncrieff Chief Executive of London Friend

there is growing concern that the needs of people with HIV are being neglected within government strategy. Furthermore, unless the government tackles mental health and HIV in a more integrated way, we will struggle to meet the 2030 target of zero transmissions and will ultimately waste resources. Positively UK<sup>22</sup> has demonstrated how peer support among people living with HIV encourages self-management and frees up clinical staff, saving local health authorities and clinical commissioning groups in the UK £5 million per year.

This report will outline the APPG's findings through our written and oral evidence of how mental health issues affect people with HIV ranging from mild to more severe conditions and some of the underlying causes of the greater incidence of mental health problems amongst people with HIV. The report will also look at current government policy on HIV, long term conditions and mental health and whether, in their current form, they meet the needs of people living with HIV. Finally, the report will make recommendations on what needs to change so that people with HIV and mental health problems are able to access the care and support they need. The report does not distinguish between mental health support and psychological support but uses the terms interchangeably to describe the different levels of mental health or psychological services available across of the Health system. Psychosocial support refers to the "mental health" services provided through HIV support services.

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22 Positively UK (2017) "Now What? The Effectiveness of Peer Support in HIV and the Need for Action"

## Report Format

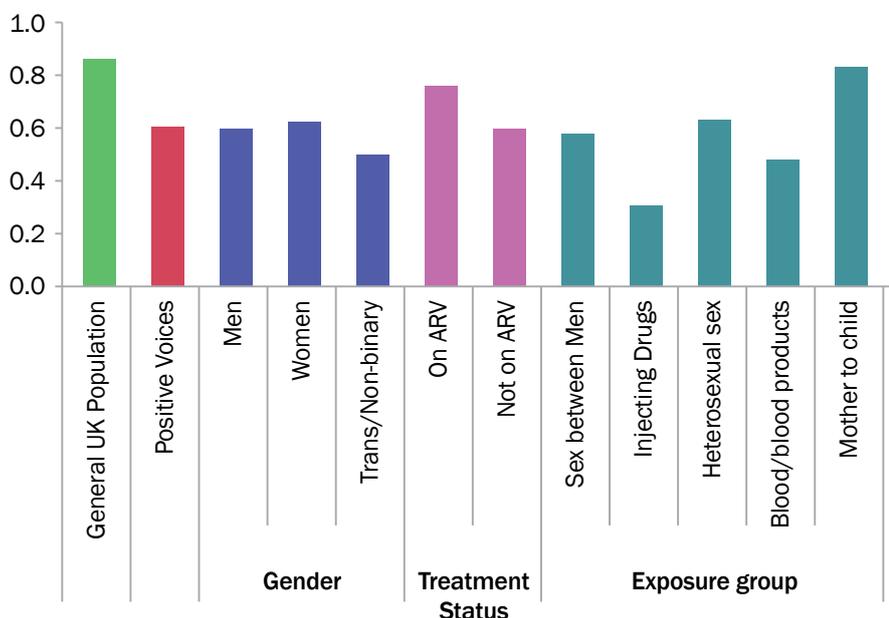
**Section 1:** Provides an overview of the impact of HIV stigma on mental health

**Section 2:** Looks at mental health triggers for people with HIV and the links between the two

**Section 3:** Looks at how mental health and HIV are commissioned

**Section 4:** Looks at what is working and where the gaps are in mental health support for people with HIV

**FIGURE 1: QUALITY OF LIFE (EQ-5D-5L UTILITY SCORES) FOR PEOPLE LIVING WITH HIV AND COMPARISON WITH THE GENERAL POPULATION<sup>23</sup>**



### REPORT FORMAT

#### Section 1

Provides an overview of the impact of HIV stigma on mental health

#### Section 2

Looks at mental health triggers for people with HIV and the links between the two

#### Section 3

Looks at how mental health and HIV are commissioned

#### Section 4

Looks at what is working and where the gaps are in mental health support for people with HIV

#### Conclusion

<sup>23</sup> BHIVA poster <https://watipa.org/wp-content/uploads/2018/08/Quality-of-Life-BHIVA-Poster-final.pdf>

# Section 1

## The link between HIV Stigma and mental health

*“If we’re serious about tackling HIV and achieving the 2030 target of zero transmissions – and we should be – then we need to get really serious about dealing with mental health issues in people with HIV”*

DR BEN SPENCER, SOUTH LONDON AND MAUDSLEY HEALTH TRUST (HIV LIAISON SERVICE)

### Why are people with HIV more likely to have a mental health condition?

The link between HIV and mental health is complex and bi-directional; however, the key underlying factor that makes HIV stand out from other long-term conditions is stigma. This report will outline how that stigma affects mental health and make the case for why psychological support for people with HIV should be included within the service specification for clinical treatment of HIV and given greater importance by the NHS. If you are diagnosed with HIV today in this country, you will receive gold standard treatment. You will have regular viral load testing check-ups and adjustments to your medication. This is not the case in many other parts of the world where there are barriers to accessing treatment. The UK’s HIV response is a leading example however, the APPG believes it needs to go further if we are going to reach the goal of getting to zero infections by 2030.

Not everyone with an HIV diagnosis will need mental health support. Mental health exists on a spectrum from mild cases of anxiety and depression to more severe cases where there are conditions such as psychosis, schizophrenia, personality disorder. Mental health conditions can pre-exist before a person is diagnosed with HIV or can be triggered by an HIV diagnosis. There are many different ways mental health issues can manifest themselves.

The aim of this report is not to say that all people with HIV have mental health needs, but that the specific characteristics of HIV make it more likely that a person will suffer from some form of mental illness and that in order to effectively treat HIV, you need to treat any co-morbid mental health issues. Poor adherence to medication leads to poor physical outcomes. It is well known that two of the key physical symptoms of depression are loss of appetite and disturbed sleep<sup>24</sup>. If a person with HIV has depression and is struggling to take care of their basic physical needs, they are more likely to stop taking their HIV medication.

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<sup>24</sup> Nancy L. Sin, PHD and M. Robin DiMatteo, PHD ‘Depression Treatment Enhances Adherence to Antiretroviral Therapy: A Meta-Analysis’ Published in final edited form as: *Ann Behav Med.* 2014 June; 47 (2): 259-269.

The link between mental health and antiretroviral adherence has been clearly demonstrated by a meta-analysis published in the 2014 American Review which demonstrated an 83% improvement rate in adherence to medication if the person was treated for depression. Greater improvements in adherence were found for samples with lower CD4 counts or more severe depression.<sup>25</sup> These results demonstrate a clear link between improvements in physical and mental health for people with HIV and depression.

## HIV Stigma

The Cambridge definition of stigma is: “a strong feeling of disapproval that most people in a society have about something, especially when this is unfair”. HIV stigma exists because many people do not realise that if you are undetectable, you are untransmittable (U=U), which means that if you are taking HIV medication, the virus is suppressed and you cannot spread HIV. Furthermore, many myths still exist around how you can contract HIV. According to the National AIDS Trust website:

“HIV is passed on through infected bodily fluids such as semen, vaginal fluids, blood, breast milk and rectal secretions. The most common ways HIV is transmitted are through sex without a condom and through sharing infected needles, syringes or other injecting drug equipment. You cannot get HIV through casual or day-to-day contact, or kissing, spitting or sharing a cup or plate. A small number of people living with HIV in the UK acquired it before or soon after birth (‘vertical’ or ‘mother-to-child’ transmission).”<sup>26</sup>

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It is well documented that sexually transmitted infections are stigmatised,<sup>27</sup> but this is exacerbated for HIV by the fact that before it was treatable it led to millions of deaths from AIDS and it still remains a life-long condition. The fear and cultural memory of HIV being a death sentence therefore pervades and increases the level of anxiety and discomfort amongst the general population who are not well versed on the reality of HIV today.

HIV stigma is also well documented and has been shown to have a detrimental impact on a variety of health-related outcomes in people with HIV, including mental health.<sup>28</sup> The HIV stigma Index UK shows that stigma continues to affect the lives of people with HIV in the UK. One in five respondents had experienced verbal harassment or threats. A third reported having their HIV status disclosed without consent by a friend or a family member. One in five also reported being treated differently by a GP.<sup>29</sup>

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25 Physical symptoms of depression as outline on the NHS website: <https://www.nhs.uk/conditions/clinical-depression/symptoms/>

26 NAT website <https://www.nat.org.uk/we-inform/FAQs-%26-Myths>

27 Very Well Health Website <https://www.verywellhealth.com/the-stigma-stds-have-in-society-3133101>

28 Rueda S, Mitra S, Chen S, et al, ‘Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses’, *BMJ Open* 2016;6:e011453. doi: 10.1136/bmjopen-2016-011453

29 The Stigma Index UK, ‘Stigma Survey UK 2015’, 2015. April 2019. Available at: <http://www.stigmaindexuk.org/reports/2016/NationalReport.pdf>

The healthcare system is a key institution where people with HIV report experiencing a significant amount of stigma. The Positive Voices survey which was carried out in collaboration with Public Health England found that one in three (35%) had been worried that they would be treated differently to other patients, 14% had actually experienced discrimination in a healthcare setting, 18% had avoided healthcare when they needed it, and 11% of people with HIV had actually been denied or refused a treatment or procedure that they needed.<sup>30</sup>

Stigma within healthcare settings is a particular area of concern for people with HIV when their only option available is to use generic mental health services because the HIV support service has been cut by their local authority. In oral evidence to the APPG, Dr Kate Reilly from the Royal Victoria Infirmary (RVI) in Newcastle highlighted:

**“We see healthcare stigma, we hear from patients that nurses are double-gloving and doctors will say things like, we don’t like sticking needles in people like you.”**

**DR KATE REILLY, RVI, NEWCASTLE**

Evidently, healthcare professionals should not be influenced by ill-founded myths about HIV and therefore HIV stigma should not exist within healthcare settings. However, the data shows that it does and therefore the government need to invest in an education or training programme for healthcare professionals across the NHS if HIV is ever going to become a more mainstream long-term condition. Additionally, given the high prevalence of mental health issues for people with HIV, they should ensure there are sufficient specialised mental health or support services available.

### **‘Actual’ and ‘Perceived’ Stigma**

The HIV Liaison Service at South London and Maudsley Trust (SLAM) highlights that in BAME communities, cultural beliefs can lead to issues around shame and stigma leading to non-diagnosis and barriers to treatment. A meta-analysis by Katz Ryu<sup>31</sup> concluded that there is a link between stigma and ARV adherence. As outlined by SLAM in written evidence to the APPG:

**“Stigma can be ‘actual’ or ‘perceived’ (“internalised”). Whereas actual stigma is a societal issue, perceived stigma is a mental health issue that occurs when an individual, as a result of repetitive external messages about HIV (for example, ‘I am dirty’, ‘nobody will accept me’), develops negative core beliefs that fuel and/or exacerbate mood disorder’.**<sup>32</sup>

30 Positive Voices Survey, ‘Changing Perceptions: Talking about HIV and attitudes’, November 2018. [https://www.nat.org.uk/sites/default/files/publications/web\\_PV\\_Changing%20Perceptions-Stigma-report.pdf](https://www.nat.org.uk/sites/default/files/publications/web_PV_Changing%20Perceptions-Stigma-report.pdf)

31 Katz, I.T., et al., Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. *J Int AIDS soc*, 2013. 16 (3 suppl 2): p.18640

32 Written evidence HIV Liaison Service, South London and Maudsley

A number of witnesses to the inquiry highlighted that specific groups are more impacted by both 'actual' and 'perceived' stigma. For example, many women from sub Saharan Africa carry stigma from their country of origin and experience HIV as a curse. This belief may lead them to stop taking medication. In some cases, this has led to premature death. This type of issue was highlighted by both SLAM and Barts Health Trust in oral evidence to the inquiry as both psychology teams operate in high prevalence areas in London where there is a high percentage of BAME communities.

The RVI in Newcastle describes stigma surrounding HIV and homosexuality in the north east. They also reiterate that stigma is more prevalent in BAME communities and during oral evidence to the inquiry highlighted the case of two black African men that needed to be relocated because of stigma:

“I’m here to tell you that HIV may well be a manageable long-term condition medically but the unique features that it comes with...leads to the need for specialist services. Stigma is alive and well in the north-east and impacts [particularly] on our Black-African cohort. We have recent examples of people being forced out of their families, workplaces and communities. Two black men were subjected to violent hate crime due to their HIV status which has culminated in the need to be relocated to different parts of the country. We also have recent examples of people dying because of stigma. A white British man ended his life only days after receiving his HIV diagnosis because he could not live with the stigma.”

DR KATE REILLY

Dr Sarah Rutter, Clinical Psychologist and Psychology Lead in the HIV Service at **North Manchester General Hospital** highlighted another case of a stigma related death in oral evidence to the inquiry:

“[In many cases]...their template for relationships is people who care for me hurt me and I think there is a real opportunity within HIV to address that model, that template they have and show them what good, consistent care can look like...Recently we had a lady who had a diagnosis about eight to ten years ago. She was so ashamed she didn’t seek any help whatsoever. By the time she came to us she had PML (Progressive Multifocal Leukoencephalopathy) and unfortunately she died... It was really, really difficult to watch and that is the power of stigma.”

## Summary

Stigma and HIV are almost synonymous and affect almost all people living with HIV. Our inquiry has highlighted a number of examples of stigma, particularly within BAME communities and MSM. Stigma is closely associated with mental health issues as it can increase a person's sense of isolation or decrease their sense of self-worth. While 'actual' stigma is a societal issue which needs to be tackled, 'perceived' stigma is a mental health issue which also needs to be tackled but with different interventions.

Stigma within healthcare settings is especially concerning as it deters people with HIV from seeking treatment either for their HIV or for other co-morbid conditions unless they are in an HIV specific clinic. This is particularly pertinent when someone with HIV is in need of mental health support, they are at their most vulnerable and therefore more likely to be deterred from a healthcare setting if it is not specialised in HIV. Within healthcare settings there needs to be an urgent education campaign about the reality of HIV today so that people are not needlessly subjected to ignorance at best, and at worst, deeply stigmatising views.

## Recommendations

- A comprehensive strategy for reducing HIV stigma in the UK is urgently needed. The response to stigma in the UK significantly lags behind the gains we have made in prevention, testing and treatment. As a first step, there should be an overarching campaign to reduce stigma across the NHS.
- BAME communities should be included in the design and implementation of any strategy to reduce stigma given the high prevalence of HIV within BAME communities and specific cultural attitudes and norms that affect treatment adherence and can increase levels of stigma.
- "Perceived stigma" is a mental health issue which requires different interventions. People with HIV who are afraid to access mainstream services because of perceived stigma need to be able access HIV specific services or health professionals who are trained in HIV stigma and its impact on mental health.

## Section 2

# Why are people with HIV more likely to suffer worse mental health outcomes?

While stigma is the underlying factor that makes HIV stand out from other long-term conditions, HIV and mental health are linked in a number of intersecting ways. People with HIV are twice as likely to experience mental health issues compared with the general population. That is partly due to stigma relating to HIV, but it is also linked to the fact you are more likely to contract HIV if you have a pre-existing mental health condition. Secondly, both mental health issues and HIV disproportionately affect the same groups such as the LGBT and BAME communities. Both HIV and mental health issues affect people that are more vulnerable, marginalised and suffer from socio-economic deprivation. Both LGBT people and BAME communities experience discrimination throughout their lives, while some BAME communities are more likely to live in areas of socio-economic deprivation.

These issues are all inter-related and when looked at in a holistic way, make a clear case for the close correlation between HIV, mental health and the need for increased investment in this area if we are serious about reaching the 2030 target of zero infections. According to Public Health figures, between 2016-2017 there was a 1% increase in late diagnosis which is 43% of all new HIV infections. Late diagnosis is already stubbornly high but this increase is concerning as it reflects the sad reality that a significant number of people would rather not know their HIV status because of the stigma associated with being HIV positive.

### People living with HIV are twice as likely as the general population to have a mental health issue

As the Positive Voices survey found people with HIV are twice as likely to experience mental health issues compared to the general population.<sup>33</sup> In Positive Voices, 50% of people with HIV reported feelings of depression or anxiety on any given day (compared to 24% of the general population).<sup>34</sup> It also found that 29% of people with HIV had been screened positive for a mental health condition compared to 19% of the general population.<sup>35</sup> The survey found that the most common mental health conditions reported by people with HIV were depression (diagnosed in a third) and anxiety (diagnosed in a quarter).<sup>36</sup> However, it also found significant experience of rarer mental health conditions such as sleep disorders (15%), post-traumatic stress disorder (5%), psychosis/schizophrenia (2.4%) and bipolar disorder (1.7%).<sup>37</sup>

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33 NAT Website, Positive Voices Survey 2018, 'Changing Perceptions: Talking about HIV and our needs' [https://www.nat.org.uk/sites/default/files/publications/web\\_PV\\_Changing%20Perceptions-needs-report.pdf](https://www.nat.org.uk/sites/default/files/publications/web_PV_Changing%20Perceptions-needs-report.pdf)

34 Ibid.

35 Ibid.

36 Ibid.

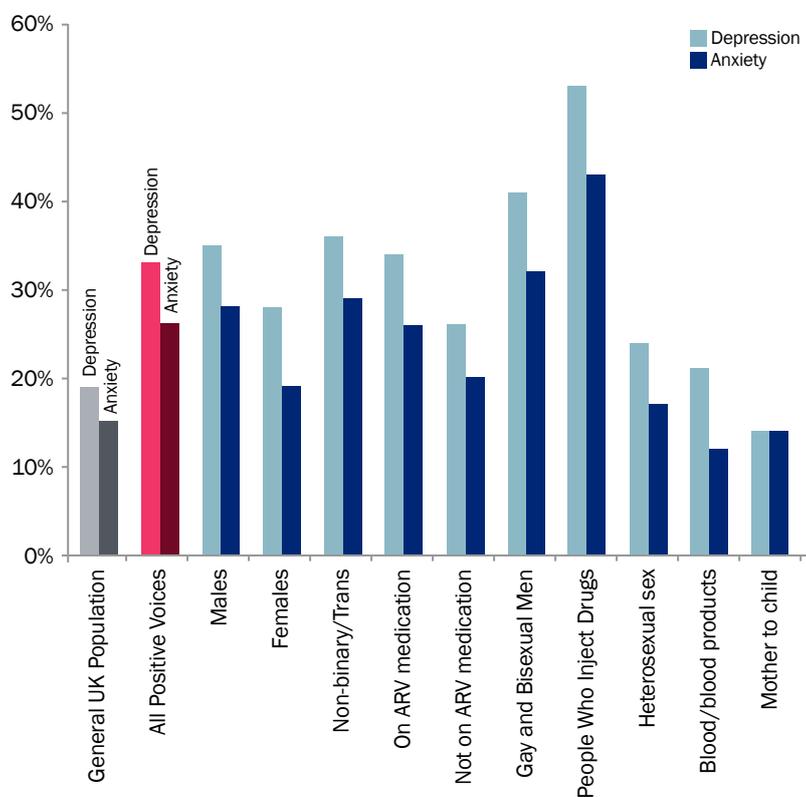
37 Ibid.

Complex and acute mental health needs also significantly affect people with HIV. A recent Lancet paper found a suicide rate for HIV positive men in the first year after diagnosis over five times higher than that for men in the general population. The Stigma Index found that 18% of people with HIV reported suicidal ideation (this was even higher among those diagnosed in the last 12 months (28%).<sup>38</sup>

**FIGURE 2: PREVALENCE OF DIAGNOSED DEPRESSION AND ANXIETY IN ADULTS LIVING WITH HIV IN ENGLAND AND WALES COMPARED TO THE GENERAL POPULATION (KELLY ET AL (2018))**

RESULTS

Self-reported prevalence of ever diagnosed with depression and anxiety (n=4,416) with comparison to the general population



- Prevalence of ever diagnosed with depression was **33%** among people living with HIV versus **19%** in the general population ( $p < 0.0001$ ).
- Prevalence of diagnosed anxiety was **26%** compared to **15%**, ( $p < 0.0001$ ).

**Gender**

- Men had higher rates of both depression (35% vs 28%;  $p < 0.0001$ ) and anxiety (28% vs 19%;  $p < 0.0001$ ) compared to women

**Treatment Status**

- Transgender/non-binary people reported the highest rates of depression (36%) and anxiety (29%)
- Prevalence of depression and anxiety did not differ by antiretroviral treatment status

**Route of Exposure**

- Men who have sex with men had two-fold higher rates of depression (41%) and anxiety (32%) compared to the general population
- Men and women who acquired HIV through heterosexual contact had similar rates of depression (24%) and anxiety (17%) to the general population
- People with a history of injecting drug use reported the highest rates of both conditions: 53% had depression and 43% had anxiety

38 Croxford S et al 'Mortality and causes of death in people diagnosed with HIV in the era of highly active antiretroviral therapy compared with the general population: an analysis of a national observational cohort' Lancet Public Health Vol 2 Jan 2017.

## The relationship between HIV and mental health is bi-directional?

The relationship between HIV and mental health is bi-directional. Evidence shows that people with pre-existing mental health problems are more likely to acquire HIV. Furthermore, once someone is diagnosed with HIV, they are more likely to experience mental health issues because of the stigma and self-stigma which some people experience, alongside the physical complications of living with a long-term condition, which we know also makes mental health issues statistically more likely. Living with a long-term health condition has a psychological dimension requiring an individual to adapt to new circumstances, which can involve impediments to function, financial stressors and social isolation.<sup>39</sup>

According to the British Psychological Society (BPS):

“People with HIV have an increased likelihood of having a trauma history and it is well documented that people living with mental health issues are more likely to acquire the condition.<sup>40</sup> Trauma, including early adverse experiences interplay with HIV acquisition. Early trauma resulting in insecure attachment styles can lead to low self-worth and mental health issues that persist into adulthood<sup>41</sup>. Those with low self-esteem and mental health difficulties may also belong to other marginalised groups (based on gender, social status, ethnicity, sexuality, etc). This in turn has the potential to exacerbate mental health problems through issues such as stigma and isolation. For these groups of people with multiple intersecting mental issues - they may lack the ability and confidence to negotiate safe sex practises, making HIV acquisition more likely.”

BRITISH PSYCHOLOGICAL SOCIETY

The BPS further highlights that people living with these issues are at risk of entering relationships where there are problems such as partner violence, threats, control and coercion which make it impossible to self-protect from risks such as HIV acquisition. Poor mental health can lead to issues relating to disinhibition, which can affect safe sex choices and a person’s ability to regulate risk. These issues are particularly pertinent in the chemsex scene<sup>42</sup>. There is also the added concern that people living with untreated mental health issues, often underpinned by complex trauma histories, are more likely to pass on the virus. This is because when service users are living with HIV and trying to manage significant mental health issues, the need to reduce their distress may

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39 Naylor, C., Das, P., Ross, S., Honeyman, M., Thompson, J. & Gilbert, H. (2016). Bringing together physical and mental health: A new frontier for integrated care. London: The Kings Fund. [https://www.kingsfund.org.uk/sites/default/files/field/field\\_publication\\_file/Bringing-together-Kings-Fund-March-2016\\_1.pdf](https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Bringing-together-Kings-Fund-March-2016_1.pdf)

40 Koegler, E., & Kennedy, C. E. (2018). A scoping review of the associations between mental health and factors related to HIV acquisition and disease progression in conflict-affected populations. *Conflict and health*, 12, 20. <https://doi.org/10.1186/s13031-018-0156-y>

41 Howe, D. (2005). *Child abuse and neglect: Attachment, development and intervention*. London: Red Globe Press

42 McCall, H., Adam, N., Mason, D., & Willis, J. (2015). What is chemsex and why does it matter? *British medical journal*, 351. DOI: 10.1136/bmj.h5790

supersede their need to manage HIV treatment, particularly if there are no immediately visible consequences of not taking medication. For example, a service user with a history of trauma, who is then further traumatised by their HIV diagnosis, may avoid complying with their HIV treatment as it acts as a direct trigger to trauma-related distress which can be overwhelming.<sup>43</sup>

The HIV Multidisciplinary team at the RVI in Newcastle further highlight the strong links between trauma and HIV acquisition in written evidence to the APPG:

“For multi-layered reasons, people living with HIV are “disproportionately burdened by trauma<sup>44</sup>” with rates of those with trauma histories many multiples of the population rate. Trauma is associated with poor health and wellbeing outcomes, poor medical adherence and increased risk behaviours that affect acquisition and transmission<sup>45</sup> and studies have found corresponding higher rates of depression, anxiety and enduring mental health issues in people living with HIV<sup>46</sup>. Mental health issues are interwoven with converging psychosocial factors such as poverty, discrimination, high risk occupations including sex work, homelessness and social isolation<sup>47</sup>. Although those living with HIV are an increasingly diverse and heterogeneous group and not all of these factors will come into play for everyone, trauma makes a huge contribution to the suffering of the people that we see in a Specialist HIV Psychology Service in the North East of England.”

DR KATE REILLY

## HIV and mental health disproportionately affect certain population groups who are affected by a combination of intersecting issues

HIV disproportionately affects population groups (LGBT and BAME communities) that are already disproportionately affected by mental health issues.<sup>48</sup> For example, research from Stonewall shows that half of LGBT people (52 per cent) experienced depression in the last year.<sup>49</sup> People from BAME backgrounds have a higher prevalence of psychosis and complex mental health needs compared with the white majority population. Black adults in the UK were also found to have the lowest treatment rate of any ethnic group, at 6.2% (compared to 13.3% in the white British group).<sup>50</sup>

43 Nightingale, V. R., Sher, T. G., & Hansen, N. B. (2010). The impact of receiving an HIV diagnosis and cognitive processing on psychological distress and post traumatic growth. *Journal of traumatic stress*, 23, 452-460.

44 LeGrand, Sara, et al. “A review of recent literature on trauma among individuals living with HIV.” *Current HIV/AIDS Reports* 12.4 (2015): 397-405.

45 *ibid*

46 Leserman J. Role of depression, stress, and trauma in HIV disease progression. *Psychosom Med.* 2008;70(5):539–45.

47 Brezing C, Ferrara M, Freudenreich O. The syndemic illness of HIV and trauma: implications for a trauma-informed model of care. *Psychosomatics.* 2015;56(2):107–18.

48 Public Health England ‘Progress towards ending the HIV epidemic in the United Kingdom 2018 report’ November 2018

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

50 Lubian, K., Weich, S., Stansfeld, S., Bebbington, P., Brugha, T., Spiers, N. ... & Cooper, C. (2016). Chapter 3: Mental health treatment and services. In S. McManus, P. Bebbington, R. Jenkins, & T. Brugha (Eds.), *Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey 2014*. Leeds: NHS Digital.

According to Black Mental Health UK, in general, people from black and minority ethnic groups living in the UK are:

- More likely to be diagnosed with mental health problems
- More likely to be diagnosed and admitted to hospital
- More likely to experience a poor outcome from treatment
- More likely to disengage from mainstream mental health services, leading to social exclusion and a deterioration in their mental health.<sup>51</sup>

According to Black Mental Health UK, people of African or Caribbean descent are 50% more likely to be referred to mental health services via the police than their white counterparts. They are also more likely to be treated under section A of the Mental Health Act.<sup>52</sup> The fact that HIV and mental health issues affect more marginalised groups like LGBT and BAME communities should be no surprise, however it is important to understand the specific cultural differences between these intersecting groups in order to effectively tailor treatment, support and prevention strategies.

All of the HIV psychology/psychiatric specialist clinicians that took part in the inquiry oral evidence sessions highlighted that it is the intersection of multiple issues which creates the unique complexity of dealing with patients living with HIV and mental health issues. As Dr Sarah Rutter representing the British Psychological Society highlighted to the inquiry: *“It is those layers of powerlessness that put you further at risk”*.

Another issue that was raised by all of the clinicians is the unwillingness of some people within BAME communities to attend groups that exist for their benefit because of the fear of stigma and that they may be “outed” in their home communities. Chris Blacktop, a psychiatric liaison nurse at South London and Maudsley Trust told the inquiry about a case of someone from Cote d’Ivoire who came to one of the liaison service groups provided in the community. His/her child, who was still living in Cote d’Ivoire, was subsequently “outed” within their own community (the fact that one of the parents was attending this group somehow got back to Cote d’Ivoire) and was then subjected to physical harassment. It is for this reason and many others that it is very difficult to reach people living with HIV in certain population groups which makes the risk to mental health even greater. As Dr Stuart Gibson from Barts Health Trust highlighted in oral evidence to the inquiry:

**“The average patient in the clinic is a single parent, Black African woman, who has three kids, one might be HIV positive, and they are living in isolation because of the complex trauma background. They might go to Church, but no-one knows about their status. They lead very isolated lives.”**

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51 Black Mental Health UK website

52 Black Mental Health UK website

## The specific challenges for young people living with vertically transmitted HIV

The Children's HIV Association (CHIVA) outlined to the inquiry how children and adolescents living with HIV have specific challenges with their mental health. Dr Amanda Williams, Chair of Trustees at CHIVA highlighted that for people who acquired HIV at birth you have population who have grown up with a chronic illness and all of the difficulty which that entails.

“We know children with chronic illnesses are more at risk of mental health issues and on top of that you have the stigma... They are families where at least one of the parents is HIV + and 80% are from the BAME community....we also know that a lot of them have lost a parent. We know that that within itself, without the HIV, contributes to poor mental health for young people on top of all these other layers of difficulty. The thing that is striking about HIV is the difficulty there is in talking within families about it...”

Whilst mental health disorders often only become apparent in adolescence or young adulthood, the risk factors giving rise to this are present from early childhood. It is therefore necessary that services are provided to address, and where possible, mitigate these risks earlier in childhood. These can include: severe HIV encephalopathy in childhood; learning disabilities and cognitive impairment; stigma, isolation and bereavement; child caring roles; self-harm, low self-esteem and finally, particularly among older children, mental health diagnoses including depression, anxiety and psychoses.

CHIVA highlighted that adolescence is a trigger point for mental health for the general population, however all of the additional factors associated with HIV make that more likely. One of the key issues to address is when a child should be informed of their status. The recommendation has changed to say that by 9 children should know their status because of the trigger point in adolescence and the difficulty some teenagers have in coming to terms with the fact they have a stigmatised sexually transmitted infection when they may never have had sex. Children living with HIV also report that it is very isolating because they are unable to speak about HIV (sometimes) within their families and with their friends at school. They carry around this “secret” for their entire childhoods and negotiating when and how to be open about their status is a very delicate matter. Openness about HIV status can certainly be met with hostility and a lack of acceptance within schools and amongst friendship groups which can make the experience extremely traumatic. It is important that school/university counselling services are trained in HIV awareness or are at least able to signpost children/families to the correct support services available in their area.

CHIVA also highlighted that moving from paediatric to adult HIV services requires support. Poor adherence to medication is particularly common amongst adolescents. As studies across the world ubiquitously find, between the ages of 14-18+, young people tend to shun taking medication consistently and may refuse to take ARVs altogether. Globally, concordance to prescribed ARVs regimens may not be higher

than 40%.<sup>53</sup> In the UK, adolescents with HIV are the only group where HIV associated mortality rates continue to rise and there is a ten-fold increase in mortality compared to the age matched general UK population. Poorer viral suppression rates in this group may also have an impact on onward transmission.<sup>54</sup> This can be due to young people reacting to being told that they are HIV positive, their experience of taking medication for years leading to “HIV fatigue”, developmental and peer-group pressure to rebel against authority and conform to peer pressure or not wanting to disclose to close friends or associates that they are HIV positive if they spend the night together.

Prolonged periods of non-adherence to medication can have serious long-term physical health complications for the young person living with HIV, including cognitive impairment which will be discussed in greater detail in the next section. It is therefore vital that there is sufficient mental health support available to young people. Currently mental health support for paediatric HIV is limited, as it is with other long-term conditions. While psychological services are included within the NHS England service specification they do not come under specialised commissioning and are therefore subject to the same fragmentation as other parts of the HIV care pathway since the Health and Social Care Act of 2012. Fragmentation of HIV care generally will be outlined in more detail in the next section.

Specialised paediatric HIV mental health services do exist but largely because of historic reasons, not routine commissioning.<sup>55</sup> Given the close link between the effects of living with long-term HIV and mental health, particularly for young people whose brains and emotions are still developing, it is particularly important that commissioning gaps do not occur, especially during the adolescent period when patients are transitioning from paediatric to adult care and are at their most vulnerable.

## Chemsex

Chemsex drug use is an increasing issue among men MSM living with HIV and these men report frequent mental health symptoms<sup>56</sup>. Chemsex is also frequently reported in MSM who are at higher risk for HIV acquisition. The use of chemsex drugs may be a way of dealing with a previously existing mental health condition, an HIV diagnosis or can directly cause mental health issues because of the chemical effects of the drugs. HIV is also closely linked, with 47% of chemsex users reporting an HIV diagnosis.<sup>57 58</sup>

According to the Chief Executive of London Friend, Monty Moncrieff – the only provider of drug and alcohol services specifically for the LGBT community: “around half of our clients say their drug use escalated following their HIV positive diagnosis and a third say their drug use only started following their positive diagnosis”.

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53 S.L. Nichols, B.Kammerer and D.E.Patton ‘Neuropsychological Outcomes of HIV in Childhood and Adolescence’, in *Pediatric Neuropsychology* (2013), I.S. Baron and C.Rey-Casserly (eds), Oxford University Press,

54 From CHIPS data 79% of children and young people are virally suppressed, compared with 97% of adults (United Kingdom HIV surveillance data tables No 2 :2019 PHE

55 NHS England HIV specification for children <https://www.england.nhs.uk/wp-content/uploads/2013/06/b06-spec-hiv-child.pdf>

56 Pufall, E. L., Kall, et al. (2018). Sexualized drug use (‘chemsex’) and high-risk sexual behaviours in HIV positive men who have sex with men. *HIV medicine*, 19(4), 261-270.

57 London Friend oral evidence

58 McCormack S, Dunn DT, Desai M, et al. Pre-exposure prophylaxis to prevent the acquisition of HIV-1 infection (PROUD): effectiveness results from the pilot phase of a pragmatic open-label randomised trial. *Lancet*. 2016;387(10013):53–60.

In oral evidence to the inquiry Monty Moncrieff highlighted that chemsex use was intrinsically linked to HIV. He stated that some people start using drugs to deal with the mental health issues they have which either pre-date or arise because of their HIV diagnosis. Equally, the acquisition of HIV is much more likely if a person engages in chemsex. Recent research by London Friend published in *Sexually Transmitted Infections*<sup>59</sup> also reflects this link between HIV status and the use of chemsex drugs. The study showed that MSM engaging in chemsex had a high prevalence of HIV (47%), that many were current or past injectors and that thoughts of suicide were common. This study was based on data which was collated by Antidote, the drug and alcohol service within London Friend because of the growing concern around chemsex as a public health issue.

As reported by AIDS MAP:

“Investigators from Antidote designed a cross-sectional study involving approximately 2300 MSM who accessed their services between 2012 and 2018....Chemsex was associated with being HIV-positive, intravenous drug use, using PEP and higher numbers of sexual partners.....”<sup>60</sup>

What this research shows is that chemsex, HIV and mental health are all very closely linked and are a particular issue amongst MSM. The Royal College of Psychiatrists also highlight a recent survey in an HIV clinic which showed that 30% of patients attending the HIV clinic used drugs regularly, up to 20% may be involved in chemsex and that mental health problems are prominent in these groups.<sup>61</sup>

As this report will outline in the next section, the current commissioning landscape is disjointed; it is therefore important to highlight how co-dependent and interlinked these specific issues are.

## Benefit changes and HIV

One issue which has been highlighted by the inquiry is the emotional and mental distress which has been caused by changes to the benefit system.<sup>62</sup> We were shocked to hear that there have been a number of suicides due to benefit reviews amongst people with HIV. The changes are complex and for people struggling with their mental and physical health, they can be overwhelming.

In 2010 the DWP announced that DLA would be abolished and replaced with a new extra-costs benefit, Personal Independence Payment (PIP). DWP said that PIP would help disabled people to “exercise choice and control and lead independent lives”.<sup>63</sup> Like DLA, PIP is a non-taxed benefit which can be paid to eligible claimants regardless of their income or whether they are in work. It also forms a ‘passport’ to other types of support (e.g. access to Motability vehicles and blue badge parking).

59 Stevens O et al. ‘Chemsex-related drug use and its association with health outcomes in men who have sex with men: a cross-sectional analysis of Antidote clinic service data’. *Sexually Transmitted Infections*: o0-1-7, doi.10.1136/sextrans-2019-054040.

60 AIDS MAP website <https://www.aidsmap.com/news/jul-2019/gay-and-bisexual-men-problematic-chemsex-are-diverse-group-significant-sexual-and>

61 Porter S, Fields M, Levitt, D, Turjanski N – Poster, “Chemsex” – ‘Assessing the Scope Of The Problem’ Liaison Psychiatry Conference, London 2017

62 Money Service Advice website <https://www.moneyadviceservice.org.uk/en/articles/benefit-changes>

63 DWP. Public consultation: Disability Living Allowance Reform. December 2010. p5.

While this issue has been widely reported within the general population, people with HIV face a further barrier to accessing support with their benefits. The ‘actual’ and ‘perceived’ stigma of untrained staff members in, for example, the companies contracted to carry out benefit assessments, means that people with HIV may either not seek support with their claims or their past trauma may be re-triggered by the benefit assessment process itself, because of a lack of understanding about the mental and physical challenges of living with HIV. A report by NAT in 2017 pointed out that DLA reassessments to date show that, compared to the overall population of people claiming DLA, people living with HIV are:

- less likely to be awarded PIP following reassessment
- less likely to receive an increase in their rate of benefit when moving from DLA to PIP
- more likely to receive a decrease in their rate of benefit when moving from DLA to PIP.<sup>64</sup>

These findings echo evidence we have heard throughout the inquiry. Dr Fiona Burns, HIV Clinical Lead at the Royal Free Hospital in London stated that benefit reviews are a mental health trigger point for her patients, stating: “as a *clinician I have had suicides because of benefit reviews*”.

Christine Stewart, Welfare Rights Officer in Newcastle highlighted to the APPG:

“My clients report increased anxiety, stress and rumination about benefit changes. These responses are no different from perhaps any other benefit claimant, especially with a longer-term health condition, and longer-term benefit dependency. However, the stigma, discrimination, fear of the diagnosis being disclosed or openly discussed adds to this stress and worry. Patients worry about DWP and other benefit agencies or employers being poorly educated of the facts around risk, adherence, side-effects of medication, longer term other health impacts and people are being reviewed more regularly by DWP. There is a revolving door.”

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64 NAT ‘PIP and HIV: ‘How Personal Independence Payment is working for people living with HIV’ 2017 <https://www.nat.org.uk/sites/default/files/publications/PIP%20and%20HIV%20Report%20online%20v.3.pdf>

The Newcastle multidisciplinary team highlighted one particularly sad case of a person who ended his life by suicide because of their benefit review:

### Case Study

Jo (pseudo name) was a single person living alone and a housing association tenant. Jo was diagnosed HIV positive in 1991. Jo had previously contracted non-Hodgkins Lymphoma, Kaposi Sarcoma and had other health issues including osteoporosis, alcohol dependency, anxiety and depression. Jo had childhood trauma issues, had worked with the multidisciplinary team in the RVI since the late nineties and had been in receipt of ESA support for many years. Jo was reviewed through a work capability assessment with the social worker present in 2013 and was found **fit for work**. Jo suffered with suicidal ideation following this decision. The welfare rights officer appealed the decision and the multidisciplinary team and social worker provided a number of evidence letters later in 2013. The decision was not revised. Jo sadly ended his/her life shortly after this decision was taken in 2014 citing the DWP decision as the reason. The welfare rights officer pursued the appeal posthumously, and the decision was overturned before the hearing (which would have been attended by a family member).

We have also received personal representations from individuals living with HIV and going through the benefit review process who have highlighted how traumatic the experience has been for them. The pervading experience seems to be that they are misunderstood, that their condition is not taken seriously and that there is a lack of awareness or understanding about the effect on a person's mental health of living with a long-term, stigmatised condition. In one person's assessment decision letter their HIV was not even mentioned. This reinforces the total lack of awareness of some untrained health professionals working for the DWP about the impact of HIV on mental health.<sup>65</sup> The process, which in many cases ends in a tribunal is traumatic for the person being assessed.

Historically HIV support services have been able to provide advice on how to access benefits however, evidence to this inquiry highlighted that the assessment process, in some cases, is causing extreme anxiety and leading to suicide. Cuts to support services also means that in some areas, there is no access to an HIV trained professional to help navigate the benefits system. When the APPG visited the RVI multidisciplinary team in Newcastle we heard a number of examples of service users that had struggled to navigate the benefits system. They are fortunate to have a specific HIV specialist Welfare Rights Officer funded by the city council, however, even with her help there have been suicides due to benefit reviews. If someone with HIV falls outside of the local authority catchment, they have no access to support from the HIV specialist welfare rights officer and their HIV support service may also have been cut. Ultimately what this shows is that there is a postcode lottery when it comes to access to support for people living with HIV.

<sup>65</sup> This is a personal case which the APPG received and reviewed the formal assessment from the DWP.

The Newcastle model is an example of good practise that could serve as a blueprint for how HIV care and support should be commissioned. The HIV specialist welfare rights officers sits within the multidisciplinary team to gain a better understanding of the service users' needs. She works with the multidisciplinary team and HIV support service to identify vulnerable patients and conducts home visits when necessary. Her knowledge of the welfare system and HIV is crucial to providing both practical and emotional support. All of the people with HIV we spoke to at the Blue Sky Trust in Newcastle talked about the importance of the welfare rights officer. They could not understate her role and importance. Christine's success in gaining the trust of people with severe mental health difficulties and HIV highlights the importance of understanding the effect of living with a stigmatised long-term health condition.

## Summary

Mental health and HIV are intrinsically linked and triggered in complex intersecting ways. Both mental health and HIV disproportionately affect the same groups because the risk factors for acquiring both conditions are either the same or similar, including socio-economic deprivation, isolation and marginalisation. People living with HIV are more likely to have a mental health condition and people with a mental health condition are more likely to acquire HIV. Children who have vertically transmitted HIV are also at much higher risk of developing mental health problems because they experience similar risk factors but from a much younger age when they are under prepared emotionally to cope with the situation, alongside the added pressure of potential parental loss due to an AIDS related illness.

Finally, benefit changes are creating increased levels of anxiety and stress for people with HIV which, in some cases, is leading to suicide. The lack of understanding about the effect of HIV on both physical and mental health is a deterrent for people struggling with benefit changes to access advice and support. This highlights the need for specialist support to be made available to people with HIV and the danger of cutting HIV support services while simultaneously making benefits harder to access.

## Recommendations

- The NHS England HIV service specification should recognise the impact of stigma on mental health and adherence to treatment and include mental health support as part of the core service.
- Chemsex should be looked at holistically alongside HIV and mental health and this should be taken into consideration when commissioning services.
- Chemsex services should be available at sexual health clinics and HIV clinics.
- Psychological and mental health support for children and young people with HIV should also form part of the service specification and given the same weighting as clinical treatment.
- School/university counselling services need to have basic HIV awareness training or at least be able to signpost to the local HIV support service.
- HIV support services are a crucial part of the care pathway and should have a clear commissioning home.
- The DWP must look again at Personal Independence Payment and whether the assessment design, criteria and current approach to scoring are suitable for a benefit designed to promote participation and independence.
- The welfare system should be sensitive to the impact of an HIV diagnosis. This could be achieved by integrating HIV-related topics and their impact on mental health into the training of assessors. There also needs to be explicit attention paid to issues around confidentiality and HIV, which takes into account the possibility that people may not disclose their HIV status due to concerns relating to stigma and discrimination.
- It is particularly important for assessors to understand the power of stigma and trauma and their potential to impact a person's ability to function on many levels. Assessors for welfare benefits should also be aware of the potential iatrogenic effects of the assessment process and pay attention to their own language and communication, which may also result in service user distress.

# Section 3

## Understanding how mental health and HIV are commissioned

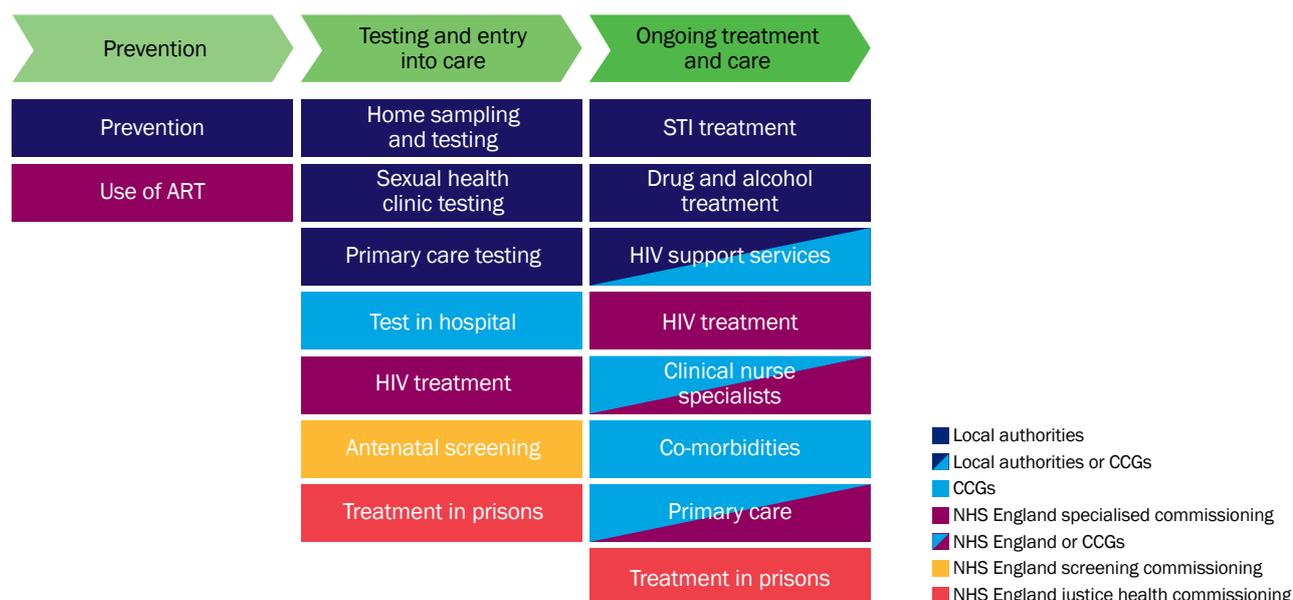
### Overview

*“...One of the biggest challenges we face is people not engaging in care because of fear of stigma. These are small communities and there is a fear that if someone should discover their status they will lose everything...”*

DR STUART GIBSON, BARTS HEALTH TRUST

To understand where the gaps are in mental health services for people with HIV you need to go back to the Health and Social Care Act 2012. As the APPG on HIV and AIDS highlighted in ‘The HIV Puzzle: Piecing together HIV care since the Health and Social Care Act 2012’, since the Act came into effect HIV services are commissioned by NHS England, CCGs and local authorities and responsibility is split across these three bodies. See the diagram below by the Kings Fund which demonstrates the split of responsibilities for HIV care across CCGs NHS England and Local Authorities.

FIGURE 3: COMMISSIONING LANDSCAPE FOR HIV SERVICES SINCE THE 2012 REFORMS <sup>66</sup>



<sup>66</sup> The Kings Fund, ‘The future of HIV services in England: Shaping the response to changing needs’, 2017 [https://www.kingsfund.org.uk/sites/default/files/field/field\\_publication\\_file/Future\\_HIV\\_services\\_England\\_Kings\\_Fund\\_April\\_2017.pdf](https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Future_HIV_services_England_Kings_Fund_April_2017.pdf)

The diagram above highlights the complexity of commissioning for HIV care. The clinical side of HIV treatment is however fairly straightforward and commissioned by NHS England. Where commissioning becomes more complex is with mental health/ psychology and psycho-social support, as well as drug and alcohol services. Within mental health services, commissioning is also split across primary and secondary care, depending on the severity of the condition. One of the main barriers to accessing mental health care for people living with HIV is that, not only is HIV care split between local authorities, NHS England and CCGs but mental health services also have their own split commissioning framework. This quote from Dr Spencer in oral evidence to the inquiry aptly highlights the complexity of commissioning arrangements:

“We are CCG funded but public health commissioned... NHS England commission the HIV service, CCGs commission the mental health service..”

In order to ensure mental health provision for people living with HIV, there needs to be a considerable level of integrated care. The health system is moving towards integrated care but there are still significant gaps that need to be addressed.

## STPs and Integrated Care Systems

Sustainability and Transformation Partnerships (STPs) were established in 2015 to enable every health and care system to come together to implement the NHS Five Year Forward View and especially its emphasis on ‘planning by place for local populations’ rather than ‘planning by individual institutions’. The focus is on integration of services and care around the individual patient and local population. STPs are 44 areas covering England where local NHS organisations and local authorities came together to draw up proposals to improve health and care in the areas they serve. Their original proposals were submitted to NHS England in 2016.

A more advanced version of the STP is the Integrated Care System (ICS), where NHS organisations, in partnership with local councils and others, take collective responsibility for managing resources, delivering NHS standards, and improving the health of the population they serve. Currently there are 14 areas of England that already have become or are near to becoming an ICS. All STPs are expected to have developed into an ICS by April 2021. The recent NHS Long Term Plan stipulated that all STPs/ICSSs must develop five-year plans outlining how they plan to deliver on the commitments in the long-term plan in their local areas and work towards greater integration. These plans are due to be submitted by the end of September 2019.

The NHS Long Term Plan wants healthcare systems to improve upon what they call the ‘triple integration’. Integration between 1) primary and secondary care, 2) physical and mental health services, and 3) healthcare and social care. This integration of physical and mental health services is of utmost importance in tackling the disproportionate impact of mental health services upon people living with HIV. STPs/ICSSs offer an opportunity to improve this integration and support better HIV health outcomes. Any discussions at STP level on how to effectively integrate physical and mental health services, and the mental health needs of those with long-term conditions, should consider HIV – particularly in high prevalence areas.

HIV would really benefit from the integration STPs offer but may well be overshadowed by the big questions of financial sustainability and more prevalent health challenges that STPs have focused on such as cancer. Mental health is a key health condition that STPs are looking at and this offers an opportunity to discuss improvements required in meeting the mental health needs in relation to HIV service users.

A recent project conducted by NAT found that while there was a limited focus on HIV in the initial 2016 STP plans, there were areas such as Greater Manchester, that had considered proposals to improve HIV outcomes, after HIV stakeholders had advocated for HIV as a priority. Greater Manchester's Population Health Plan has committed to a vision of ending all new HIV transmissions within a generation. To that end, the healthcare system has agreed a workstream and is providing £1.3 million of additional funding over the next two and a half years to meet the aim. While healthcare in Greater Manchester is devolved, and the system there is more mature than other STPs/ICSs, this demonstrates what can be achieved at STP/ICS level.

STPs will not in and of themselves fix the current fragmentation in HIV care. They at best provide a framework within which the responsible bodies (NHS England, CCGs, local authorities, Public Health England, and local providers) can improve integration. However, they provide a vital level at which to advocate for mental health services that meet the needs of people living with HIV. By bringing together different commissioners and providers, a well-integrated HIV care pathway can be formulated which ensures that mental health services are accessible and competent at discussing HIV-related issues. Whether it is improved access to mental health provision through HIV clinics, better integration between HIV clinics and generic mental health services to ensure the HIV competency of generic services, or the provision of peer support and wider emotional wellbeing support provided by HIV voluntary sector services – these are key elements to advocate for at STP level.

## Summary

The commissioning of HIV and mental health services is extremely complex because of the split responsibility for commissioning across two separate but overlapping conditions. Since 2013 local authorities hold the public health budget and therefore some of the commissioning for HIV and mental health sits within their remit. Secondary care is commissioned by NHS England for both HIV and mental health and CCGs are responsible for commissioning a large part of the mental health budget within primary care. Commissioning of mental health services for HIV is divided into four different levels and responsibility at these different levels is often split between different commissioners.

The fragmentation within the health system as a whole since the Health and Social Care Act has been well documented and recognised by the Government. STPs and ICSs are attempting to address some of this fragmentation by providing the opportunity for health providers to look holistically at health needs within a specific area. While to date, HIV has not featured within many of the STP plans, they provide a vital level at which to advocate for mental health services that meet the needs of people living with HIV. By bringing together different commissioners and providers, a well-integrated HIV care pathway can be formulated which ensures that mental health services are accessible and competent at discussing HIV-related issues.

## Recommendations

- STPs should be assessing how improvements on the integration between physical and mental health services can be made.
- STPs, especially those in high prevalence areas, should be considering HIV-related issues as part of the development of their new five-year plans and their ongoing workplan.
- NHS England should be considering how STPs/ICSs can ensure integration of and improvements in mental health and HIV.
- Local HIV stakeholders should take the initiative in developing proposals for STP consideration and persist in advocating for them.

# Section 4

## Where are the gaps in mental health services for people with HIV?

The provision of mental health services for people living with HIV in England is varied throughout the country. In some areas there are excellent services (see examples below), however, significant gaps do exist. These gaps are more evident in mild to moderate levels of mental health need and in specific areas of the country. This section will outline how mental health services are working on the ground at the various locations people with HIV would access mental health support including the HIV clinic, HIV support services, Increased Access to Psychological Therapy (IAPT - which is through primary care) and through drug and alcohol services (local authorities).

The British Psychological Society, alongside MEDFASH and BHIVA developed the Standards for Psychological Support for Adults Living with HIV (2011)<sup>67</sup>. These standards include a stepped care model which outlines what level of support should be available to people with HIV along four different levels of mental health need.<sup>68</sup>

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67 The British Psychological Society et al. 'Standards for psychological support for adults living with HIV' 2011

### The Stepped Care Model

BHIVA Standards of Care 2018 and BHIVA Monitoring Guidelines state that all PLHIV should be screened at least once a year for mental health problems, and within three months of initial diagnosis, and where needed onward referral should be organised. These referral pathways should be agreed across four levels of psychological support (ranging from least to most complex). These levels of support are explored in more detail in the 2011 BHIVA Standards for psychological support for adults living with HIV.

The British Psychological Society have provided this very useful summary of the stepped care model.

The stepped care model proposes four levels of psychological need, the assessments and interventions required at each level and which healthcare professionals are responsible for the provision of this support.

- All HIV healthcare professionals are required to deliver level one support, which includes understanding psychological issues associated with HIV, recognising overt distress, responding to distress with supportive communication, provision of relevant information and signposting.
- Level two describes a need for enhanced support, such as screening for distress and cognitive difficulties, risk assessment, discussions around acceptance and adaptation, education sessions, brief behavioural interventions and signposting. This would generally be delivered by HIV Specialist Nurses/Advanced Practitioners or clinicians with relevant additional training.
- At level three, clinicians trained in the delivery of a specific mode of psychological therapy/ counselling (e.g. cognitive behavioural therapists) assess and formulate psychological problems and risk and deliver psychosocial interventions for specific psychological difficulties.
- At Level four, specialist mental health professionals (e.g. Clinical Psychologists and Psychiatrists) are required to carry out in-depth assessments and interventions, including formulation of longstanding, complex and inter-relating psychological difficulties, neuropsychological assessments and cognitive rehabilitation, ongoing risk assessments and the delivery of psychological and psychiatric interventions for severe mental health issues.

As the complexity of mental health issues increases, the level of recommended support also increases commensurately. Additionally, as healthcare practitioners will have contact with service users with all levels of psychological need, professionals with specialist mental health qualifications should provide support to the whole team through activities such as consultation, supervision, facilitation of reflective practice, teaching and training.

68 Standards and a model of care for children and young people have also been developed: 'Psychological Management of Children and Young People Living with HIV: Standards for Care 2014'. [https://www.chiva.org.uk/files/6415/4454/4932/PsychologyStandards-summary\\_2018.pdf](https://www.chiva.org.uk/files/6415/4454/4932/PsychologyStandards-summary_2018.pdf) written by Paediatric HIV Psychology group (PHP) and endorsed by CHIVA, Faculty for HIV & Sexual Health (BPS) and PPN (Paediatric Psychology Network)

Research for our inquiry highlighted that the stepped care model is working well in some areas but in many parts of the country there are either significant gaps or it is almost impossible to know what exists where, because there is no systematic way of commissioning mental health services for HIV. This makes it extremely difficult to hold commissioners to account.

Overall, the evidence suggests that at levels 3 and 4 where secondary care is involved, specialist HIV mental health provision is better than at levels 1 and 2 where service users are expected either to access HIV support services, which are under constant threat of de-commissioning or generic mental health services which are not necessarily appropriate for people with HIV. Drug and alcohol services are also particularly difficult to access because they are commissioned by local authorities and the links between mental health, HIV and chemsex are not currently reflected in the siloed commissioning structure.

## HIV Clinics

Evidence to the inquiry demonstrated that the implementation of the stepped care model is extremely varied throughout the country and that collecting information about the services available is difficult because there is no effective monitoring system in place. As Dr Nora Turjanski representing the Royal College of Psychiatrists pointed out in oral evidence:

“When I received this request we found it very very difficult to trace services and I think that is because services have grown up organically, probably without knowing where services sit, which services are still working and which services are being de-commissioned. It is very difficult to trace.”

There are two key surveys which highlight that there is uneven uptake of the standards, however these surveys do not demonstrate where services are, or are not, in place. According to the British Psychological Society:

“The National Nurse led Audit of the Standards for Psychological Support for adults with HIV (NHIVNA 2015) showed that 40% of the services that responded did not have a mental health professional (psychologist, mental health nurse, liaison psychiatrist or social worker) in their team.... There was a distinct lack of psychological screening, and particularly low levels of cognitive screening, and for over half of the services that responded there was a lack of documentation of mental health history and risk.”<sup>69</sup>

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69 Ibid

The BHIVA audit found that only 73% of HIV clinics asked about mental health problems on their proforma for annual clinical review.<sup>70</sup> Similarly, only 49% of HIV services had a clinical lead for psychological support.<sup>71</sup> Given that 50% of people with HIV report mental health problems, these figures should be much higher.<sup>72</sup> BHIVA concluded that HIV services varied widely in both routine assessment of psychological well-being/mental health and substance use and reported psychological status among assessed individuals.

During oral evidence to the inquiry we heard that even in London there is limited provision of the full stepped care model. At the time of writing this report, Dean Street, one of the largest sexual health providers in the country only has a part time liaison psychiatric nurse. Their health advisors report that they struggle to meet the high demand with limited resources, space and training.

The BHIVA audit also looked at provision of mental health care within HIV clinics. Even within HIV clinics, the audit showed that only 63% of HIV services offered psychological/mental health support.<sup>73</sup> As highlighted by NAT, integral to the success of developed care pathways and mental health provision for people with HIV is the inclusion of a psychologist/mental health professional on MDTs in HIV services<sup>74</sup>. The audit found that of all service users assessed 19.7% were found to either have a significant level of distress or likely to have a diagnosable psychiatric illness.<sup>75</sup> This highlights the importance of increased uptake of BHIVA standards.

## What is working well and where are the gaps in HIV clinics?

### SOUTH LONDON AND MAUDSLEY HIV LIAISON SERVICE

Two key examples of a good HIV Psychology service are the South London and Maudsley HIV Liaison Service and the Specialist Psychology Service at the Royal Victoria Infirmary in Newcastle upon Tyne.

The South London and Maudsley Service covers the area of highest HIV prevalence in the country. Dr Ben Spencer, a consultant liaison Psychiatrist explained to the APPG how their service works:

**“As much as possible we try to do liaison with a capital ‘L’. We embed ourselves in the acute hospital... we embed ourselves in the HIV community services... seeing people in Guys and St Thomas’...in Lewisham hospital... seeing people at home or at the outpatient clinic... whatever is most appropriate for the setting. We can see someone within a fortnight, but occasionally see people within 24-48 hours if needed... we have excellent commissioners and an excellent service.”**

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70 BHIVA 'National Audit 2017: Psychological well-being and support, and use of alcohol and recreational drugs', November 2017. <https://www.bhiva.org/file/toHvyakKUZRqp/SarahParry.pdf>

71 Ibid.

72 Positive Voices Survey, 'Changing Perceptions: Talking about HIV and our needs', November 2018 [https://www.nat.org.uk/sites/default/files/publications/web\\_PV\\_Changing%20Perceptions-needs-report.pdf](https://www.nat.org.uk/sites/default/files/publications/web_PV_Changing%20Perceptions-needs-report.pdf)

73 BHIVA 'National Audit 2017: Psychological well-being and support, and use of alcohol and recreational drugs', November 2017. Accessed 8th April 2019. Available at: <https://www.bhiva.org/file/toHvyakKUZRqp/SarahParry.pdf>

74 NAT written evidence

75 Ibid.

According to Dr Spencer, one of the most worrying issues which psychiatric clinicians face today in HIV is cognitive impairment. Cognitive impairment is a medical condition which affects many people and is not restricted to people living with HIV. Alzheimer's is the most well-known form of cognitive impairment.<sup>76</sup> In HIV cognitive impairment can be as a result of the direct impact of infection in the brain, the impact of HIV on the developing brain in the vertically transmitted young people, and cerebral insults associated with HIV infection. He states that "some evidence suggests that merely having HIV is a risk factor for cognitive impairment but this is a very complex area to study; many people living with HIV also have other risk factors that increase the risk of cognitive impairment".

In other words, you can take ARVs from the moment of diagnosis, and ensure your blood levels are always under control but may still be more susceptible to contracting a form of cognitive impairment. As people live longer with HIV there is an ever-increasing importance to support people to live healthier for longer. Outside of HIV control, there are many other risk factors that people can modify to prevent cognitive decline, such as managing high blood pressure, stopping smoking, and preventing diabetes and these should be a priority for all professionals working with people living with HIV.

HIV can lead to cognitive impairment because of the direct effect of viral replication in the brain and other cerebral insults associated with HIV infection.<sup>77</sup> According to one study, neurocognitive impairments are not universal among HIV infected persons, however, clinically obvious signs and symptoms of at least mild neurologic disease are found in approximately 30% of persons with asymptomatic HIV infection and about 50% of individuals with the acquired immunodeficiency syndrome (AIDS)<sup>78</sup>.

Evidence to the inquiry highlighted the prevalence of cognitive impairment and developmental issues in young people who have vertically transmitted HIV and people who have lived with the virus for many years. Young People who were born with HIV have had no time during which to develop without their immune system being under the attack of HIV. Therefore, at times of great developmental changes, the HIV positive young person's immune system is unable to function freely and wholly, resulting in a variety of effects including the potential of impaired cognitive development.

Depending on how long it takes for the child to be found HIV positive, the negative effects of the virus can be dramatic. According to the HIV Liaison Service in South London and Maudsley Hospital Trust (SLAM), antenatal HIV screening has largely consigned this picture to the past, but there are HIV positive young people who did not start taking ARVs until they were 6,7 or later), whose neuropsychological assessment shows cognitive issues - quite often, lower than expected Speed of Information Processing, attentional difficulties, some level of Dysexecutive Function (difficulties in inhibiting unwanted/negative responses), and slowness in thinking.

76 Cognitive impairment is when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe. With mild impairment, people may begin to notice changes in cognitive functions, but still be able to do their everyday activities. Severe levels of impairment can lead to losing the ability to understand the meaning or importance of something and the ability to talk or write, resulting in the inability to live independently. Centre for Disease Control [https://www.cdc.gov/aging/pdf/cognitive\\_impairment/cogimp\\_poilicy\\_final.pdf](https://www.cdc.gov/aging/pdf/cognitive_impairment/cogimp_poilicy_final.pdf)

77 Written Evidence HIV Liaison Service, South London and Maudsley NHS FT, London, UK

78 Heaton, R. K., Grant, I., Butters, N., White, D. A., Kirson, D., Atkinson, J. H., et al. (1995). The HNRC 500—Neuropsychology of HIV infection at different disease stages. *Journal of the International Neuropsychological Society*, 1, 231–251.

According to the SLAM service who work with this client group there is a sustained “return to clinic” and increased resilience in dealing with the reality of HIV in the post-adolescence period, with young people confronting their denial of HIV and the avoidance of clinics/hospital, developed by many since their early life has often been characterised by multiple admissions. Nonetheless, a small number of young people continue to be admitted to hospital with so-called “AIDS-defining illnesses” - because of prolonged non-adherence; these opportunistic infections are very serious and present the clinicians with the more nefarious aspects of untreated HIV infections, so common in the 80s and 90s and unfortunately still not completely consigned to the history of this virus. Non-adherence is a consequence of poor mental health and therefore addressing mental health issues amongst young people is crucial to improving clinical outcomes.

One of the key points that came out in oral evidence is the difficulty in diagnosing cognitive impairment and the need for specialist HIV psychiatric expertise within MDTs to ensure people are accurately diagnosed and then able to get the right treatment. In HAND (HIV-associated Neurocognitive Disorder), a form of dementia and other related neurocognitive disorders, some symptoms may be able to be reversed if diagnosed early, it is therefore crucial that all HIV clinics have access to appropriate expertise within their MDT.

#### **ROYAL VICTORIA INFIRMARY, NEWCASTLE UPON TYNE**

Dr Kate Reilly is a Principal HIV Clinical Psychologist working in the Specialist HIV Psychology Service at the Royal Victoria Infirmary in Newcastle as part of the Newcastle upon Tyne Hospitals NHS Foundation Trust. The team consists of 2.4 whole time equivalent Psychologists working under a Consultant Psychologist who leads the team and is responsible for the psychological support of people living with HIV. The team work with a wider psychosocial multidisciplinary team of doctors, nurses, social workers, a Specialist Welfare Rights Officer and representatives from a voluntary sector support agency, the Blue Sky Trust, who support people locally living with HIV. They meet weekly to discuss and agree plans of support for those with, often complex and multifaceted, psychosocial needs. The team have received training to skill them up to Level 2 of the BHIVA Stepped Care Model, so that they feel confident in screening for mental health needs and offering brief interventions or appropriate referrals onwards.

People with identified psychological needs can be referred in, or self-refer, and they operate with often a minimal waiting list, allowing them to be responsive and to see both inpatients and outpatients. They currently only have a Level 4 provision, so any psychological needs identified are assessed by a Clinical Psychologist. They will then offer ongoing work or signpost as appropriate.

Their therapeutic work is diverse and incorporates issues such as adjustment to diagnosis and taking medication, assessing and supporting cognitive difficulties and supporting people with depression, anxiety, sexual difficulties, drug and alcohol misuse and sleep issues. They use evidence-based models such as Eye Movement Desensitisation and Reprocessing (EMDR), Cognitive Behavioural Therapy (CBT) and Cognitive Analytic Therapy (CAT). A large proportion of the work they do is focussed around understanding and managing the impact of trauma and stigma in people’s lives at different levels.

Having HIV expertise is crucial in fostering trust with the people they see. There is also often an advocacy role in supporting disempowered people often from around the world to be heard in complex systems. This could involve writing benefits reports, asylum reports and attending child protection meetings. They are also developing groups in community settings, such as the Start Making Sense trauma psychoeducation group and an Acceptance and Commitment Therapy Group, both sited at, and run in

conjunction with, the Blue Sky Trust. Signposting could be to primary care services if the issues are unrelated to HIV and mild in nature, to specialist drug and alcohol services for specific specialist support or to other specialist services such as perinatal mental health, early intervention in psychosis or Community Mental Health Teams.

Joint working is often clunky as these people will work for separate organisations and the flow of information is often slow or non-existent. The exact organisation will also depend on where the individual lives so good working relationships with other agencies can be hard to build up. Difficulties arise because of commissioning arrangements, which see some people in the service able to access the whole range of professionals, and others without access to social work or specialist welfare rights support (for example). All people accessing the HIV clinics in the North East should have information about the services that they provide, however the recent Positive Voices survey reflects that this does not always happen.

Kate states:

“The gaps are in identifying complex issues, finding ways in and around cultural barriers...and sometimes communication about what’s available...we have run groups with the local HIV support service that are undersubscribed because people don’t know about them or stigma prevents them from taking up the opportunity...”



Members of the APPG visit the Blue Sky Trust and the multidisciplinary team at the RVI in Blue Sky Trust office in Newcastle upon Tyne

## HIV support services

The Health and Social Care Act 2012 left some commissioning gaps, the most notable was the lack of a responsible commissioner for support services. That gap has resulted in a number of HIV support services being cut by local authorities with ever constricting budgets. According to the Health Foundation, local authority public health grant funding

is being cut by £700 million in real terms between 2014/15 and 2019/20. This equates to a reduction of almost a quarter in public health spending per person.<sup>79</sup> An assessment conducted by NAT showed that expenditure on HIV support services in England dropped by 28% between 2015/16 and 2016/17.<sup>80</sup>

HIV support services are a crucial part of psycho-social support for people with HIV and are recommended in the BHIVA guidelines to be included as part of a holistic HIV response<sup>81</sup>. However, without a commissioning home, they are under threat and there are various examples across the country where support services have been completely decommissioned, leaving a massive gap in the HIV care pathway. According to NAT, outside of London, 8.4% of English local authorities terminated all expenditure on support services in 2016/17.<sup>82</sup>

Open-access support services have been a key part of the national response to HIV since the beginning of the epidemic in the 1980s. They can include information, advice and advocacy; peer support; and psychosocial support, for example. Peer-Support has been recognised as an essential part of patient centred care by the 'Standards of Care',<sup>83</sup> an evidence-based guideline mapping the best care for people with HIV. The evidence around the ability of peer support to improve mild mental health problems is still being researched, however, it has been proven to have a positive impact on health and well-being, addressing isolation and improving self-confidence.<sup>84</sup>

These services are usually, though not exclusively, delivered by the voluntary sector, and provide a model of long-term condition management. HIV support services equip people living with HIV to live well and deal with issues which disproportionately affect this population, including stigma, poverty, poor mental health and social isolation. Specific groups living with HIV, for instance older people, newly-diagnosed people, women, black African people, migrants and younger people can especially benefit from specialised services.

The complexities in families with children and young people living with HIV needs to be recognised. The impact of HIV compounds when parents and children both live with HIV within a family. HIV can put significant strain on family relationships. A family-based approach to address these psychosocial impacts is needed, and this needs to be accessible via clinic-based support services. CHIVA successfully provides this model of support in some areas of UK. Once engaged with support within clinic it is more likely that young people will access other out of clinic support programmes such as the CHIVA support camp for children and young people, or arts-based support for young adults.

Research by NAT has identified that 35% of people living with HIV had accessed support services in the past 12 months. Services for people living with HIV provide support in dealing with issues more likely to affect them than the general population including poverty, co-morbidities, mental and emotional health problems, and employment and housing problems. For many people living with HIV, these services are a rare safe space where they can discuss HIV and its impact.

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79 Health Foundation analysis

80 NAT (National AIDS Trust), 'HIV support services – The state of the nations', April 2017. [https://www.nat.org.uk/sites/default/files/publications/NAT\\_HIV\\_Support\\_Services\\_The\\_state\\_of\\_the%20nations%20\\_2017\\_FULL.pdf](https://www.nat.org.uk/sites/default/files/publications/NAT_HIV_Support_Services_The_state_of_the%20nations%20_2017_FULL.pdf)

81 Standard 6 in the BHIVA Standards of Care: "People living with HIV should receive care and support that assesses, manages and promotes their emotional, mental and cognitive well-being and health, and is sensitive to the unique aspects of living with HIV" [https://www.guidelines.co.uk/infection/bhiva-standards-of-care-for-people-living-with-hiv/454178.article#a\\_Knowledge\\_and\\_training](https://www.guidelines.co.uk/infection/bhiva-standards-of-care-for-people-living-with-hiv/454178.article#a_Knowledge_and_training)

82 NAT "HIV Support services: state of the nations", 2017 <https://www.nat.org.uk/sites/default/files/publications/NAT-HIV-Support-Services-The-state-of-the-nations-2017-EXEC-SUMMARY.pdf>

83 British HIV Association 2018, 'Standards of Care for People Living with HIV'

84 Positively UK, 2014 'Improving well-being the effectiveness of peer support'

In spite of a clear need for these services, disinvestment in HIV support services is a proven trend in England. Over a quarter of local authorities in England cut contract values by at least 50%. In Scotland and Northern Ireland services remained steady over the years considered.<sup>85</sup> The evidence around the benefits of peer support is still growing. Recent analysis of peer support and person-centred approaches to health, carried out as part of ‘Realising The Value’ – an NHS England funded initiative to provide a stronger understanding of the value of community, person centred interventions to health and well-being<sup>86</sup>, recognises that peer support benefits the health and wellbeing of individuals including clinical outcomes, better adherence and understanding of health conditions.

Peer support has also been found to create economic benefits by reducing pressure on other health and social care services. According to Realising the Value’s economic modelling, provision of peer support can save up to £2,100 per-person per-year to the health system. Furthermore, by reducing anxiety and depression, improving self-management and individual well-being, peer support has the potential to contribute up to £20,800 per-person per-year in terms of wider social support.<sup>87</sup>



Members of the APPG (Lloyd Russell Moyle MP, Stephen Doughty MP, Baroness Baroness Barker, Lord Collins of Highbury, Lord Black of Brentwood), HIV organisations (NAT, THT, Positively UK) and representatives from BHIVA and BASSH at an APPG oral evidence session in June 2019

85 NAT press release <https://www.nat.org.uk/press-release/exposed-huge-national-cuts-hiv-support-services>

86 Realising the Value (2016) Economic Model for Commissioners <https://media.nesta.org.uk/documents/what-the-system-can-do-the-role-of-national-bodies-in-realising-the-value.pdf>

87 Ibid

## IAPT

The Improving Access to Psychological Therapies (IAPT) programme began in 2008 to increase treatment of anxiety disorders and depression. The Five Year Forward View for Mental Health<sup>88</sup> committed to expanding access to IAPT. From April 2018 all clinical commissioning groups are required to offer IAPT services integrated with physical healthcare pathways. The IAPT Pathway for People with Long-term Physical Health Conditions and Medically Unexplained Symptoms guidance<sup>89</sup> is intended to help with implementation and sets out the ideal pathway for IAPT services.

This increased access to mental health support for people living with a long term condition is certainly positive however, evidence to the inquiry highlighted a number of concerns about the suitability of IAPT for people living with HIV, particularly if IAPT is going to replace what traditionally HIV support services have provided in terms of psycho social support. Primary care (including IAPT) now support nine in every ten people accessing mental health care in England.<sup>90</sup> There is not much evidence of the acceptability or effectiveness of IAPT for 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 IAPT curriculum.

According to the Psychology Service in the Infection & Immunity Department at Barts Health NHS Trust in East London, making referrals to IAPT Long Term Condition services should be happening if these primary care services can demonstrate that their staff members are both competent and confident in providing such care. The national curriculum for training IAPT workers does not include HIV, sexual diversity, psychosexual problems or 'talking about sex'. As a result, IAPT workers do not possess the 'core competencies' for providing support to people who present with such problems. Local ad-hoc training is being provided in some key areas such as South London, but this is not an effective or reliable remedy for training gaps in the IAPT industry.<sup>91</sup>

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 services users feel comfortable talking about their status and associated issues. According to the British Psychological Society, "IAPT uses a CBT framework, which may not be suitable for the complex and longstanding issues that are often observed within the HIV population."<sup>92</sup>

There is urgent need for further evidence on acceptability of IAPT for people with HIV and on outcomes. The NHS Long Term Plan detailed how NHS England will continue to expand access to IAPT services for adults and older adults with common mental health problems, with a focus on those with long-term conditions.<sup>93</sup> While there has been development on long-term condition management within the NHS and its connection with mental health needs, this work has largely focused on very common conditions such as cancer, diabetes, and cardiovascular disease. HIV has not yet been considered within the framework of bettering the mental health of those with a long-term condition.

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88 Independent Mental Health Taskforce to the NHS in England 'Five year forward view for mental health' (2016) <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>

89 NHS Website <https://www.england.nhs.uk/publication/the-improving-access-to-psychological-therapies-iapt-pathway-for-people-with-long-term-physical-health-conditions-and-medically-unexplained-symptoms/>

90 NHS England, 'Adult Improving Access to Psychological Therapies programme' <https://www.england.nhs.uk/mental-health/adults/iapt/>

91 Written Evidence South London and Maudsley Health Trust

92 Written Evidence British Psychological Society

93 NHS England, 'The NHS Long Term Plan', January 2019. <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf>

Given the pressure on local authority budgets to cut support services, where traditionally people living with HIV would be able to access psycho social support and the budget constraints within the NHS which mean that HIV mental health specialists are the exception not the norm within MDTs, there is a considerable gap in support for people with HIV and co-morbid mental health conditions. The key question is how this gap should be filled and whether IAPT is suitable as an alternative given that we don't yet have much concrete data to demonstrate it is effective. Evidence to this inquiry highlighted that if people with HIV are referred to generic services they are more likely to be lost to care because of perceived and actual stigma within healthcare settings around HIV. Furthermore, this could impact on clinical outcomes and adherence to ARVs.

## Drug and alcohol services

According to the South London and Maudsley HIV Liaison Service, 'mental health services and addiction services have often created a conflict when a person has a dual diagnosis need, a patient can be sent between the different services with neither wanting to case hold.<sup>94</sup> Local authorities are responsible for drug and alcohol services while mental health services are commissioned by CCGs. This is further complicated by the fact that sexual health services are open access while drug and alcohol treatment services are for catchment area only. Equally acute mental health care is open access while primary mental health services are catchment area only. Services and long-standing relationships between HIV, sexual health and drug/alcohol services can be disrupted by procurement processes as commissioners are under considerable pressure to achieve cost savings. As highlighted by Dr Nora Turjanski in oral evidence to the inquiry:

**“Acute hospital care is not under catchment area and mental health provision is, which always creates a lot of conflict at the interface and I think that is part of why it doesn't work. It's difficult to maintain relationships with so many different teams”.**

The South London and Maudsley HIV Liaison Service highlight that they are in a unique position of having a specialised HIV Mental Health Liaison Team whose role is to provide support for complex services users including chemsex, drug and alcohol issues. The provision of risk reduction interventions and treatment of the drugs used in chemsex is however, patchy with no mandated service or standard service model. According to the Royal College of Psychiatrists “some services have established referral pathways, but this does not appear to be universally embedded.”<sup>95</sup>

According to the British HIV Association (BHIVA) most men with chemsex problems attend sexual health and HIV services on a regular basis and their use of drugs is closely linked to their sexual behaviours and risk of other sexually transmitted infections. Evidence to the inquiry highlighted that there is an increasing frustration amongst clinicians that drug and alcohol services will not accept service users with chemsex issues while their drug use also excludes them from receiving primary mental health care creating a “catch 22” situation. The APPG agrees with BHIVA and others that there is a good argument for providing chemsex drug use services as part of risk

94 South London and Maudsley HIV Liaison Service written evidence

95 Written evidence Royal College of Psychiatrists

reduction interventions within sexual health/HIV clinics as part of holistic sexual health care. As highlighted by the South London and Maudsley Service this type of provision is not currently routinely commissioned, although it does exist in some parts of the country.

The Department of Health and Social Care should recognise the need for better integration of these closely linked health issues and ensure there is sufficient guidance in place for commissioners to provide holistic care for people with HIV, drug use and mental health issues. The disjointed commissioning is leading to increased diagnoses of both HIV and untreated mental health conditions.

## Summary

The Stepped Care Model for HIV Psychological Support provides a holistic guide for mental health provision which should be available for people living with HIV, however implementation of these guidelines is patchy and there is no standard system for monitoring uptake of the guidelines. This is leading to gaps in mental health provision for people with HIV.

Evidence to the inquiry shows that HIV support services are under the constant threat of local authority cuts and the increased focus on IAPT as the future for mental health support for people at levels 1 and 2 of the stepped care model is not necessarily appropriate for people with HIV because of the actual and perceived stigma within healthcare settings. Furthermore, the strong link between HIV and trauma means that CBT based therapy is not necessarily the most appropriate course of treatment for someone suffering with long term mental health issues.

Chemsex, mental health and HIV are all closely linked and should be treated in an integrated way, however, evidence submitted to the APPG highlights that chemsex issues are currently falling through commissioning cracks because of the complexity of the system. There needs to be recognition by NHS England that these issues are closely connected and the commissioning landscape should be simplified to enable more joined up services.

Cognitive impairment related to HIV adds another dimension to the discussion on mental health as it is a relatively new area of study and is becoming more relevant as people live longer with HIV. Lack of specialist knowledge within hospitals and MDTs about cognitive impairment in people with HIV means that people are not receiving the treatment or diagnosis they need. Young people who have lived with HIV since they were born are exhibiting signs of cognitive impairment at a very young age compared with the general population. These cognitive issues require specialist understanding and treatment and if diagnosed early enough, can be reversible.

## Recommendations

- Increased implementation of the BHIVA Standards of Care and Monitoring Guidelines are needed across HIV services in the UK, ensuring that more HIV services are assessing mental health needs amongst service users, ensuring 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.
- All HIV services should be assessing how to offer psychological support within the HIV service. Given the prevalence of mental health problems amongst people with HIV and the need to overcome fragmentation and barriers to mental health services within the healthcare system, HIV clinics offer an ideal setting to provide psychological support.
- Psychological support is needed for paediatric and young people's services to allow early identification of neurocognitive difficulties and family focussed support through to transition into adult services.
- All HIV clinics should include a psychologist on their MDT and access to a psychiatrist with HIV expertise.
- NHS England should assess whether provision of psychological/mental health support should form a part of the national service specification for HIV services given the high prevalence of mental health issues amongst people with HIV. This could help overcome any commissioning barriers to the provision of mental health services.
- NHS England should assess the HIV competency of IAPT services in areas of high HIV prevalence. This could form part of NHS England's ongoing work to improve IAPT services for people with long-term conditions.
- Generic services should never be proposed as an acceptable alternative to HIV-specific services when those generic services are under-resourced, failing to meet demand appropriately even without HIV positive service users, and where staff of such services have not been meaningfully and effectively trained on HIV issues.



# Conclusion

Mental health and HIV are connected in a number of intersecting ways. One of the key underlying factors that makes people living with HIV twice as likely to suffer from mental health conditions is the pervading existence of stigma. However, stigma is not the only reason there is an increased incidence of mental health issues amongst people with HIV. The relationship between HIV and mental health is bi-directional. People with HIV are more likely to have a mental health problem and people with mental health issues are more likely to contract HIV.

HIV disproportionately affects groups that are already disproportionately affected by discrimination and marginalisation such as the LGBT and BAME communities. There is a strong correlation between HIV, socio economic status and socially marginalised groups. These links all highlight the importance of tackling mental health and HIV in a joined-up way.

Since the Health and Social Care Act, the commissioning landscape is complex and fragmented for many disease areas, let alone multimorbid and comorbid conditions, although there is a growing consensus that whole person-centred care is the direction of travel. The new pathway for mental health and long-term conditions is an opportunity for HIV and mental health to be addressed more holistically. However, the main source of treatment is currently CBT based through IAPT. Evidence to our inquiry shows that people with HIV are deterred by mainstream mental health services because of the stigma which they have experienced within healthcare settings and that shorter CBT based therapies are not necessarily well suited to some of the mental health issues around HIV. Equally, there is concern that the IAPT curriculum is not suitable to deal with issues around sex and stigma and that there needs to be better training of the IAPT workforce if this is the direction of travel for people with HIV suffering from anxiety and depression.

There are a number of serious issues which are currently not being given sufficient attention by NHS England. Chemsex is a growing public health concern and the links between HIV, mental health and drug use are well documented. Currently chemsex is falling through commissioning gaps because mainstream alcohol and drug services are not set up to deal with chemsex drugs and primary care mental health services are not able to deal with addiction issues. This gap is being filled by the voluntary sector but funding is insecure and unsustainable without proper investment.

Children and young people living with HIV have very specific needs around mental health which are not currently being met by the health services. They are more likely to suffer from psychosis than adults living with HIV. Mental health services for children living with HIV do exist but they are not part of NHS England commissioning. One way of ensuring both adults and young people are able to access the mental health support they need is by including clear referral pathways for mental health within the service specification for HIV. Given the close links between HIV and mental health and the clear impact on improved adherence to medication and health outcomes, it seems evident that a stronger focus on mental health is needed within HIV clinical treatment.

The recommended 'Stepped Care Model' for HIV and mental health is not being fully implemented across the country and it is currently difficult to assess what is available for people with HIV. Lack of monitoring and resources appear to be the main issues. Even within London where there are high prevalence areas there are big gaps in HIV psychological care and this is impacting both on patients and staff who are looking after people with complex needs but are not necessarily trained to address their issues.

While the UK continues to provide world leading clinical treatment of HIV, stigma and poor mental health continue to hold back the response. If we are truly serious about ending the epidemic by 2030 then we need to start addressing mental health, HIV stigma and the indisputable links between them. The current commissioning landscape is too fragmented and ultimately leads to service users missing out on a better quality of life and in some cases, tragically, leads to loss of life all together.

Note: This report was compiled before the General Election in 2019 when Dr Paul Williams and Jeremy Lefroy were both members of parliament and officers of the Group. We are very grateful for their contribution to the inquiry and report. In particular, Dr Williams visited the multidisciplinary team in Newcastle as part of this inquiry. We would like to acknowledge their valuable contribution to the Group during their time as members of Parliament.

# Annex 1

## Organisations who gave written evidence

South London and Maudsley Trust HIV Liaison Service	NAZ
Psychology team at the Royal Victoria Infirmary (RVI), Newcastle Upon Tyne	Positively UK
Royal College of Psychiatrists	THT
The British Psychological Society	CHIVA
Dean Street Chelsea and Westminster Hospital	The HIV Psychosocial Network
Barts Health Trust	Brighton and Sussex University Hospitals
BASHH	ViiV Healthcare
NAT	Metro
	Gilead

## Oral Evidence witnesses

Dr Nora Turjanski Royal College of Psychiatrists  
Dr Kate Reilly – Royal Victoria, Infirmary Newcastle Upon Tyne  
Dr Sarah Rutter – British Psychological Society  
Dr Ben Spencer LLM PhD MRCP MRCPsych MAcadMEd – South London and Maudsley HIV Liaison Service  
Chris Blacktop RMN, BSc Hons, BAAC – South London and Maudsley HIV Liaison Service  
Dr Stuart Gibson Stuart Gibson - Clinical Psychologist at Barts Health NHS Trust  
Dr Iain Reeves - BHIVA  
Ian Green - Terrence Higgins Trust's Chief Executive  
Dr Fiona Burns PhD - BASHH  
Chris Hicks - National AIDS Trust  
Dr Amanda Williams - CHIVA  
Silvia Petretti - Positively UK's CEO  
Harun Tulunay  
Professor John Newton FRCP FFPH FRSPH - Director of Health Improvement at Public Health England (PHE)  
Monty Moncrieff MBE - Chief Executive of London Friend  
Elaine Cunnea -NAZ

## Members of the APPG inquiry committee

Stephen Doughty MP  
Lord Black of Brentwood  
Paul Williams MP  
Lloyd Russell Moyle MP  
Baroness Barker  
Lord Collins of Highbury  
Jeremy Lefroy MP  
Catherine McKinnell MP

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# Notes

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