## Standards of Psychological Support

for Adults Living with HIV 2025









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## **Executive summary**

The British HIV Association (BHIVA) Standards of Psychological Support 2025 provide a comprehensive, evidence-based framework for delivering effective psychological care to adults living with HIV. Updated from the 2011 version, the 2025 Standards are designed for all stakeholders in HIV healthcare, including people living with HIV, psychological practitioners, service managers, commissioners, policymakers, and researchers across statutory, private, and third sectors. The goal is to promote inclusive, equitable, and high-quality care across diverse settings and delivery models, improving psychological, cognitive, emotional, and physical health outcomes.

Despite significant advancements in HIV care over the past decade such as new treatments and the widespread promotion of Undetectable=Untransmittable (U=U), people living with HIV still face stigma and emotional distress that affect their mental health. This can make it challenging to maintain self-care, such as adhering to medication regimens, which may harm physical health and contribute to continued HIV acquisition. Specialised psychological care is crucial to address the unique challenges of HIV and the specific needs of marginalised groups, which often extend beyond the scope of general mental health services.

These Standards advocate for an integrated approach that considers the biological, psychological, and social dimensions of HIV. By applying them in service design and delivery, Multidisciplinary Teams (MDTs) can offer comprehensive, culturally sensitive, and person-centred care tailored to the needs of people living with HIV. Evidence demonstrates that this approach directly improves quality of life and, by fostering better engagement with treatment and care, leads to enhanced overall health outcomes.

These Standards introduce key updates to enhance psychological support for people living with HIV:

- Person-centred language based on the <u>People First Charter</u> [1]
- Care tailored to individual needs via a matched care model (replacing stepped care model)
- Integration of regular psychological assessments throughout HIV care
- Prioritisation of culturally competent, inclusive care for diverse needs
- Strong argument for embedding mental health professionals in HIV multidisciplinary teams
- Psychology business case template
- Practical suggestions including screening tools and training options
- Good practice examples to optimise both in-house psychology and services without it
- Incorporates the latest research evidence to enhance care quality and health outcomes
- Provides psychological guidance aligned with current health policy and best practice
- Introduces new indicators to evaluate service effectiveness while minimising the administrative burden.

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These Standards present eight key areas to enhance psychological support for people living with HIV:

- 1. Promotion of mental health and wellbeing
- 2. Comprehensive psychological support services
- 3. Engagement of people living with HIV
- 4. Support around the time of diagnosis
- 5. Identifying psychological support needs
- 6. Competence to provide psychological support
- 7. Coordination of psychological support
- 8. Evidence-based practice.

The 2025 Standards are designed to be adaptable across different settings and delivery models, ensuring that psychological support is effectively integrated into HIV care. Implementation requires collaboration among healthcare providers, psychological practitioners and community organisations to create coordinated care pathways that reflect local needs and resources. The standards provide a practical framework which should be supplemented by evolving professional guidelines, UK government policies and national reports for the purpose of promoting good practice, reducing service variability and ensuring consistent quality of care.

To achieve these goals, the Standards provide practical tools such as business plan templates and good practice examples, indicators to monitor and evaluate services, suggestions for assessment and screening tools, signposting to training resources, and guidance for commissioning services. The document is framed and supported by evidence which fosters a culture of inclusivity, compassion and excellence in care, contributing to a more equitable and effective HIV response across the UK.

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#### Overview of standards

#### Standard 1: Promotion of mental health and wellbeing

#### Summary

People living with HIV should receive care which promotes their emotional, cognitive, psychological and behavioural wellbeing, and which is sensitive to the unique aspects of living with HIV.

#### Recommendations

- **1.1 Psychological wellbeing on the agenda:** people living with HIV should have the opportunity to discuss their psychological wellbeing during all clinical appointments.
- **1.2 HIV-sensitive care:** people living with HIV should receive confidential, non-stigmatising and culturally competent care informed by the unique HIV-related factors affecting psychological wellbeing. All verbal and written communications must use people-first terminology.
- **1.3 Informed psychological wellbeing:** people living with HIV should receive information and resources to support their psychological wellbeing, along with access to peer support and patient representatives during health and social care interactions.

#### Standard 2: Comprehensive psychological support services

#### **Summary**

People living with HIV should have access to a range of psychological support services appropriate to their needs.

#### Recommendations

- **2.1 Psychological support leads:** HIV services should have a designated clinical lead for psychology embedded in HIV leadership teams to oversee all aspects of psychologically informed care.
- **2.2 Psychological assessment:** assessment (i.e. in-clinic conversations, psychological and cognitive screening and in-depth psychological assessment) should be inclusive, present throughout all aspects of HIV care and appropriate for diverse needs.
- **2.3 Matched care model:** the matched care model should guide all service and care planning and access to culturally competent psychological support at Levels 1 through 4.



- 2.4 Access to interventions: clear local pathways to psychological support should follow the matched care model and communicated to HIV MDTs. These should prioritise in-house HIV specialist interventions and HIV third sector organisation support. Non-HIV specialist services must meet the needs of people living with HIV effectively.
- **2.5 Timely access:** interventions should be delivered promptly according to need, with support plans communicated as soon as the need is identified.
  - Non-urgent Level 1 and 2 needs should be responded to immediately with compassionate, context-sensitive communication and prompt signposting.
  - Non-urgent Level 3 and 4 needs requiring specialist support should have a referral-to-treatment time of no longer than 18 weeks, as per national guidelines.
  - Urgent Level 4 needs should be referred immediately to emergency mental health services and assessed or triaged in accordance with NICE and other national guidelines.

## Standard 3: Engagement of people living with HIV

#### **Summary**

People living with HIV should be engaged in the planning, delivery and evaluation of psychological support services.

#### Recommendations

- **3.1 Coproduction in service planning, development and evaluation:** people living with HIV should be engaged in the planning, delivery and evaluation of psychological support services, namely:
  - Designing, redesigning and developing specialist HIV services.
  - o Participating in evaluation activities to inform service management.
  - o Co-developing outcome measures for psychological support services.
  - Shaping local and national HIV policy and research agendas.
- 3.2 Supporting coproduction: HIV specialist services should implement EDI policies and inclusive frameworks to ensure involvement from all communities affected by HIV. People living with HIV engaged in service improvement and delivery should be provided with supervision, training and opportunities to enhance their skills as needed.
- 3.3 Including The HIV community in service delivery: people living with HIV should play an active role in delivering HIV and specialist psychological support services through peer support, advice and advocacy. All HIV specialist services should either provide direct peer support or have established pathways to external providers to ensure access as needed.



**3.4 Commissioning and remuneration**: HIV community organisations should be commissioned to support co-production and people living with HIV should receive remuneration for the work they carry out.

#### Standard 4: Support around the time of diagnosis

#### Summary

People living with HIV should have timely access to information and appropriate emotional support following the diagnosis of HIV.

#### Recommendations

- **4.1 Support at the time of diagnosis:** people living with HIV should receive appropriate psychological and emotional support following their diagnosis. In healthcare and community settings, the person delivering the diagnosis should offer emotional support, collaborate on a plan of care which includes addressing immediate psychological needs and ensure appropriate follow-up. All practitioners delivering results should be culturally competent, well-informed and compassionate.
- **4.2 Information at the time of diagnosis:** self-testing kits, healthcare settings and community testing services should provide up-to-date written information on HIV and signposting to reputable online resources. Healthcare and community practitioners should also provide high quality verbal information along with written materials.
- 4.3 Psychological support following diagnosis: all people newly diagnosed with HIV should have assessment of psychological, emotional and cognitive wellbeing, using screening tools if needed. Any referral for psychological support should be based on the matched care model. Local policies and pathways for post-diagnosis psychological support and referral must be in place. Urgent needs identified through clinical conversations should lead to immediate referrals.

#### Standard 5: Identifying psychological support needs

#### Summary

People living with HIV should have access to psychological screening as part of routine investigation and monitoring of HIV and cognitive screening as needed.

#### Recommendations

- 5.1 Routine screening: within HIV clinical settings:
  - Clinicians should have exploratory conversations about psychological wellbeing at all routine, non-routine and walk-in appointments.
  - Screening tools should be used if indicated, to assess for low mood/depression, anxiety, substance use, cognitive difficulties or PTSD.



- Suicide or self-harm risk should be explored through thorough needs-based assessment, using a risk formulation approach.
- Routine psychological screening should take place at least once per year.
- **5.2** Additional screening: people living with HIV should have access to screening following events that are known to trigger or exacerbate psychological distress or cognitive difficulties.
- **5.3 Referral following screening:** clear, inclusive pathways for further assessment to a suitably competent practitioner must be in place for those whose screen suggests significant difficulties.

#### Standard 6: Competence to provide psychological support

#### Summary

People living with HIV should have their psychological support provided by competent practitioners.

#### Recommendations

- 6.1 Competence to provide psychological support: psychological support should be provided by trained practitioners with proven competencies (aligned with the matched care model) in both their specialism and HIV. In-house specialists working with HIV MDTs are essential for optimal care. In non-specialist settings, practitioners must gain a thorough understanding of HIV through training, CPD and collaboration with HIV experts.
- 6.2 Maintenance and assessment of competence: all practitioners providing assessments and interventions should maintain their psychological and HIV-specific competence through CPD, reflective practice and receiving proactive supervision. Individuals practising at all levels of the matched care model have an ongoing responsibility to maintain competence, supported by their employing organisation. Competence should be assessed both formatively and summatively through ongoing supervision, personal development reviews, observation of practice and verbal feedback.
- 6.3 Training: specialist HIV psychological practitioners (matched care model Levels 3 and 4) must keep their HIV knowledge updated and should offer in-house training, supervision and CPD to Level 1 and 2 MDT members. Where there is no in-house psychology, HIV MDT members must access psychological skills training through validated and reputable training courses. In non-specialist settings, HIV champions should be appointed to ensure the communication of specialist knowledge and to challenge misinformation and stigma.



## **Standard 7: Coordination of psychological support**

#### Summary

People living with HIV should have access to appropriate psychological support services that are coordinated within a managed framework.

#### Recommendations

- 7.1 Service design and provision: psychological support should be integrated into all phases of planning, design, delivery and evaluation of services accessed by people living with HIV. Commissioners, clinical leads, people living with HIV and other important stakeholders should work collaboratively to ensure high-quality, well-coordinated, inclusive psychological support across all levels of the matched care model.
- 7.2 Pathways of care: care pathways between HIV treatment providers and psychological support services should be explicit, agreed upon by all partners and include self-referral options. Coordination across services should ensure that psychological support is available as needed, with a focus on transitions between services and throughout different life stages.
- 7.3 Leadership and collaboration: psychological support must be underpinned by effective collaboration across organisational and professional boundaries, supported by clear, accountable leadership. Clinical leadership should come from Level 4 practitioners with HIV expertise, integrated into multidisciplinary HIV care teams, working closely with commissioners and local service leads. Knowledge, skills and resources should be shared across disciplines/services to ensure trauma-informed training, maintain competencies and advance interdisciplinary research on the health and wellbeing of people living with HIV.
- 7.4 Inclusivity and accessibility: Psychological services should be designed and coordinated in accordance with the diverse needs of people living with HIV. Psychological care pathways should be developed in a manner responsive to all ages gender identities, ethnicities and sexual orientations and language barriers to care and information addressed. Special attention should be given to those facing complex disadvantage. All referral mechanisms should be clear and accessible.

#### Standard 8: Evidence-based practice

#### **Summary**

All psychological assessments and interventions for people living with HIV should be based on the best available evidence.

#### Recommendations



- **8.1 Evidence-based assessment and interventions:** all psychological assessment and intervention methods used across the four levels of matched care should be selected and delivered according to the best available evidence of effectiveness.
- **8.2 HIV-appropriate assessment and intervention methods:** all psychological assessments and interventions should be selected based on their suitability for people living with HIV and/or other complex long-term conditions.
- 8.3 Contextualised assessment and intervention methods: all psychological assessment and interventions methods should account for contextual factors known to impact people living with HIV in the UK, such as biomedical, socio-cultural, environmental and economic influences.



## Introduction

## The evolving landscape of HIV care in the UK

Recent estimates suggest that 104,058 people are currently living with HIV in the UK [2-5]. Since British HIV Association (BHIVA), the British Psychological Society (BPS) and MedFASH published the first Standards for Psychological Support in 2011, the UK landscape of HIV care has evolved significantly:

- Consensus around U=U (Undetectable = Untransmittable) confirms that people living with HIV who consistently maintain an undetectable viral load cannot transmit HIV to others [6-8].
- Anti-retroviral innovations and optimisation have expanded treatment options,
   minimised side effects, and alleviated certain aspects of psychosocial burden [9, 10]
- People who started ART from 2015 onwards, or who started before 2015 with a high CD4 cell count, can expect a life span close to that of the general population [11]
- Screening and early identification of HIV in antenatal services has resulted in very low levels of vertical acquisition [12, 13].
- Testing developments, including opt-out testing, home testing, and digital partner notification, are improving confidential access to information about HIV status [14-17].
- The implementation of Post-Exposure Prophylaxis (PEP) and Pre-Exposure Prophylaxis (PrEP) has significantly decreased new diagnoses and strengthened overall prevention efforts [18, 19].

Despite these developments which have helped transform HIV into a manageable long-term health condition, people living with HIV continue to experience substantially higher rates of psychological distress compared to the general population (20-22) including depression, anxiety and severe mental health difficulties [23]. HIV is also more common in people who use mental health services than in the general population [24].

## A resilient population

It is important to acknowledge that, despite an incredibly complex and difficult history, the HIV population is made up people who have survived all kinds of adversity. The HIV community built a support system around itself, for adults, and for children, young people and their families, creating a platform for empowerment and activism. Many people who are diagnosed with HIV are able to adjust to and manage their condition, using their own capacity and the support of the systems around them. Whilst noting that there are people living with HIV who thrive, this document focuses on the needs of those who are caused distress by socio-cultural-political factors connected to the condition [25, 26].



## The need for psychological support

Psychological health is considered fundamental to the quality of life for those living with HIV [27-29]. Physical and mental health conditions are closely entwined, with interactions between clinical presentations often exacerbating symptoms, complicating treatment regimens and ultimately worsening overall health outcomes [14, 30]. This interplay not only results in higher mortality rates but also drives increased demand for healthcare services and escalates service costs [14, 31]. Psychological interventions have been shown to yield beneficial impacts for both physical health issues and mental health problems (32).

As such, psychological health and quality of life are key goals for HIV programmes alongside clinical outcomes [33-35]. In the UK, adult mental health support is provided by a network of NHS, third and private sector organisations (Hub of Hope). Most operate independently of wider healthcare services, and only a few have specialist knowledge about HIV and its unique impacts on mental health, which hinders the delivery of effective support that meets the mental health needs of people living with HIV [36]. Minority groups in the UK face greater challenges in accessing psychological support due to barriers such as stigma, discrimination, services not being tailored to their needs, limited availability, and a lack of trust in providers [17]. These challenges are particularly severe in rural areas and underserved locations, where access to specialist HIV mental health services is especially limited [37-39].

## Understanding the complex interplay of HIV and mental health

Many individuals living with HIV lead fulfilling lives supported by the significant medical advancements that have been made. However, HIV remains a particularly complex biopsychosocial illness, deeply intertwined with inequality, stigma, and discrimination. As a result, a substantial body of evidence shows that many people living with HIV continue to face considerable mental health challenges, including higher rates of anxiety, depression, trauma, sleep problems, psychosexual issues, and suicidal ideation compared to the general population [20, 40-42]. The prevalence of self-reported mental health conditions among people living with HIV is 39.4%, significantly higher than the 13.5% reported in the general population and the 16.7% recorded in the Adult Psychiatric Morbidity Survey [43, 44].

## The psychological impact of an HIV diagnosis

HIV is a lifelong, incurable condition that profoundly affects both physical and mental health. Stigma and the social impact of HIV can make diagnosis deeply shocking, unexpected, and life-changing, with little sense of normalisation [45]. An HIV diagnosis can also significantly affect intimate relationships, particularly when intersecting identities are present [46] and has important ramifications for major life events such as pregnancy [47, 48]. For those with a history of trauma, an HIV diagnosis can be especially distressing, with long-term consequences for both physical and mental well-being [49].

For those diagnosed before the availability of ART, the experience was particularly traumatic, as there was no effective treatment, and an HIV diagnosis was widely seen as a death sentence. This occurred within a climate of fear, reinforced by public campaigns that contributed to severe stigma [10, 50]. Depending on the stage at diagnosis, individuals may



already be experiencing physical illness, and those diagnosed at a late stage may face serious conditions requiring hospitalisation, adding further psychological and emotional distress [51, 52].

Following diagnosis, many experience grief, while some develop depression or anxiety, which can reduce motivation for care and treatment adherence [53]. People with disabilities, long-term conditions, and comorbidities often face poorer mental health outcomes in treatment programmes generally, highlighting the need for specialised support [14, 22, 54-57].

#### Links between trauma, ACEs and mental health

HIV diagnosis can often be re-traumatising, as many people living with HIV have existing trauma linked to structural inequality, marginalisation, discrimination, and adverse childhood experiences (ACEs) [40, 58, 59].

It is well documented that ACEs, where there is a lack of support to process the trauma, can have a cumulative, detrimental effect on social and emotional development as well as physical and mental health [59-61].

ACEs are often interpersonal in nature, and the resulting complex trauma means that many people living with HIV experience high levels of distress, often affecting their relationships. This can understandably complicate social functioning and has implications for both community and healthcare engagement [62, 63].

A history of trauma, including adverse childhood experiences (ACEs), increases the likelihood of acquiring HIV and negatively affects adjustment to diagnosis, engagement in care, and adherence to ART [40, 64-67].

#### ART, treatment burden, and mental health

Current guidelines recommend that all individuals diagnosed with HIV are offered ART within two to four weeks of diagnosis, regardless of CD4 count. This means the initial shock of diagnosis is coupled with the knowledge that lifelong daily medication is required [68]. While newer treatments commonly cause short-term side effects, ART-related side effects and treatment inconvenience continue to be linked to poorer mental health outcomes [69]. Many antiretroviral drugs widely used in the early 2000s were later discontinued due to their toxicity, which included neurological and psychiatric complications [70]. People who have lived with HIV for a long time are likely to have experienced significant side effects from earlier ART regimens, some of which have had lasting effects such as pain, fatigue, body shape changes, and associated psychological impacts [71].

HIV and mental health have bidirectional effects, influencing treatment adherence and overall well-being. PTSD and HIV share neurobiological mechanisms that affect treatment response, making targeted interventions essential (68). Non-adherence to HIV treatment is often linked to trauma, adversity, and psychological difficulties sometimes serving as a survival strategy to cope with distress [15, 72-74].



Issues relating to mental health and adherence must also be understood in the context of polypharmacy, defined as the use of five or more medications [75]. Many people with HIV experience polypharmacy, especially as they age, which increases the potential for adverse drug reactions and interactions [68]. It also contributes to "medicine burden," where the reliance on medication to maintain daily life and the complexities of managing treatment regimens impact overall well-being [76].

#### Cognitive function and mental health in HIV

Although the direct impact of HIV-related neurological inflammation has significantly reduced with the effectiveness of ART, cognitive changes are commonly reported among people living with HIV and are influenced by multiple interacting factors, including treatment side effects, age-related comorbidities, and menopause [77-80]. Psychological distress and coping strategies, such as alcohol and substance use or smoking, can further impact cognitive function [79, 81, 82].

#### Ageing with HIV and mental health challenges

These challenges become more significant as people with HIV age, as they are more likely to develop comorbid and multimorbid health conditions, including cardiovascular, bone, and renal diseases, frailty, and certain cancers, all of which can have significant mental health implications [83-89]. Women living with HIV who transition through menopause may experience multidimensional health and well-being challenges, potentially at an earlier age, with high levels of psychological distress [90, 91].

Nearly half of those diagnosed with HIV in the UK are aged 50 or over (5). Psychological resilience can decrease over time, not necessarily due to age, but due to the length of time living with an HIV diagnosis, which contributes to higher rates of depression, anxiety, chronic pain, and other health issues [87, 92].

#### Links between HIV stigma and mental health

HIV remains a highly stigmatised condition, with both direct and indirect links to mental health outcomes. A recent study found that 99% of participants experienced HIV-related stigma in multiple forms, including self-stigma, public stigma, and professional stigma [93], which was often reinforced by family members and peers. HIV stigma can lead to social rejection, strained relationships, and feelings of worthlessness and loneliness [94, 95] and is associated with higher rates of depression, anxiety, alcohol use disorders, and suicidal ideation among people living with HIV [95-99].

Stigma is associated with negative emotions such as self-blame, guilt, and shame, which discourage individuals from seeking diagnosis and treatment [100-101]. It also compels individuals to conceal their HIV status and acts as a barrier to accessing treatment, particularly for those with multiple intersecting stigmatised identities who experience compounded stigma and heightened psychological impacts [51, 102-105].



#### Causes and persistence of HIV stigma

HIV stigma persists due to its association with socially sensitive topics and the lasting impact of early public health campaigns and pre-treatment fears, which continue to shape perceptions today [50]. This stigma is further reinforced by the criminalisation of HIV, which is linked to negative mental health outcomes and deters people from sharing their status and accessing treatment [106-108].

HIV stigma can be understood within broader theories of health-related stigma. Many health conditions are stigmatised, and the literature has identified common factors influencing societal attitudes [109]. Stigmatised health conditions are often characterised by attributes such as the perceived level of threat they pose, moral judgments regarding their cause or culpability, and their impact on social relationships [110]. These attitudes often arise from overly simplistic, generalised, or inaccurate assumptions that lack medical justification [111].

#### HIV stigma, structural inequalities, and marginalised groups

Health stigma intersects with other forms of stigma that reinforce power dynamics privileging dominant groups while marginalising those with perceived non-normative statuses [112]. Stigma operates at multiple levels through a network of sociopolitical structures and interpersonal dynamics that create and sustain social inequality [113], resulting in feedback loops [114] that drive health inequalities [102]. All forms of stigmatisation are therefore considered persistent public health challenges [115] due to their negative impacts on population health [116].

HIV disproportionately affects marginalised and historically disadvantaged populations that are more likely to experience structural inequalities, including global majority communities, men who have sex with men, transgender and non-binary individuals, people who inject drugs, sex workers, and prisoners [117]. These groups, which have protected characteristics under the Equality Act 2010, experience intersecting HIV stigma and discrimination, resulting in cumulative disadvantage and further exacerbating disparities [58, 118].

#### The impact of structural inequalities

Laws criminalising HIV disproportionately impact already marginalised populations, with wellbeing impacts exacerbated for those facing multiple forms of marginalisation based on sexual orientation, race, gender, or class [106, 108]. Intersectional stigma increases the risk of marginalisation, depression, anxiety, trauma, low self-esteem, suicidal ideation and cumulative disadvantage [119]. Among underrepresented groups, these issues also contribute to poor ART adherence [72, 73, 120].

Structural inequalities remain a major barrier to ending HIV/AIDS [121], as stigma and discrimination increase the likelihood of HIV acquisition, deter people from getting tested and lead some to disengage from healthcare [122, 123].

#### Challenges experienced by key populations living with HIV in UK

Certain populations face distinct and overlapping barriers to HIV care, often compounded by stigma, discrimination and socio-economic inequalities. These challenges contribute to



poorer mental health outcomes, lower engagement with healthcare and difficulties in adhering to treatment.

- Black African communities face significant barriers to HIV care, including higher rates of late diagnosis, which complicates testing and treatment. Stigma, fear of discrimination and socio-economic challenges further contribute to poorer physical and mental health outcomes [124, 125]. Barriers to engaging in care are strongly influenced by social and structural determinants, as well as stigma and discrimination [126, 127].
- Men who have sex with men experience increased psychological distress and barriers to accessing care. Stigma and complex issues such as chemsex have been linked to difficulties in ART adherence, leading to challenges in maintaining viral suppression and reducing acquisition risk [128-130].
- People living with HIV who inject drugs face multiple complex issues, including lower rates of viral suppression, unmet mental health needs and increased vulnerability to various health complications. Recreational drug use is linked to higher rates of depression and anxiety, especially among women [5, 129, 131, 132].
- Transgender and non-binary individuals living with HIV report lower life satisfaction, poorer health-related quality of life, and higher unmet mental health needs compared to other people living with HIV [51, 133, 134]. Multiple layers of stigma, discrimination, and violence act as chronic stressors, leading to elevated levels of anxiety, depression, PTSD, psychosis, body image and eating disorders, self-harm, and suicide [135, 136].
- Young adults living with HIV, particularly those who acquired it vertically, face unique challenges, including trauma from the loss of family members to HIV and difficulties transitioning between services during adolescence [5, 137]. Sharing HIV status with partners, friends, and family can be particularly stressful, leading to complex family dynamics [138]. HIV-related experiences and messaging within families can cause relationship complications [139, 140]. These young adults are more likely to have experienced ACEs, psychological distress and utilise avoidant coping strategies such as substance use which can negatively impact adherence and wellbeing [141-143].
- Women living with HIV face multiple challenges, including mental health issues, violence linked to their HIV status, housing instability and complexities around pregnancy and menopause [144-148].
- Asylum seekers and refugees often experience physical and sexual violence, torture, trafficking, discrimination, bereavement, and forced separation from family members, which frequently result in PTSD and depression [149, 150]. High levels of trauma and distress are common [151, 152], and ongoing post-migratory stressors, such as poverty, uncertain legal status, housing issues, isolation, changes in status and social roles, discrimination, and fears around detention and deportation further exacerbate psychological distress [58, 153]. Barriers to accessing healthcare include fear of systems, cultural and linguistic barriers, and limited health literacy, all of which contribute to poorer physical and mental health outcomes [154-156].



## The importance of specialist psychological support in HIV care

Specialist psychological support is essential for people living with HIV due to the complex interplay between diagnosis, trauma, treatment burden, comorbidities, stigma and the high prevalence of mental health challenges. The urgent need for accessible, specialised psychological interventions is widely recognised [101, 157].

Traumatic stressors and HIV-related symptoms significantly reduce quality of life, reinforcing the need for psychological support throughout HIV care [49, 158]. Groups most affected by HIV face heightened vulnerability to mental health challenges alongside additional barriers to psychological support that must be considered [22, 36]. Access to mental health services is often hindered by stigma, racism, homophobia, and transphobia. Culturally competent, specialist services are necessary to ensure equitable access and engagement with care [22, 36].

Intersecting challenges highlight the urgent need for accessible, specialised and culturally competent psychological support for people living with HIV. Such support must be tailored to specific populations to improve quality of life and reduce acquisition risk. Trauma-informed care is particularly necessary to address the lasting effects of adversity and ensure that healthcare settings support rather than re-traumatise individuals [72, 73, 120].

There is a robust evidence base demonstrating that psychological interventions in physical healthcare settings are both effective and economically beneficial [32, 159, 160]. Specialist healthcare interventions should focus on building trust, addressing complex psychosocial needs and incorporating stress management and psychological therapies to improve adherence and health outcomes [49, 158].

## Integrating psychological support into HIV care

Specialist psychological support integrated within HIV care is crucial for addressing ongoing, complex needs through a multidisciplinary approach [63, 161]. A collaborative approach between HIV community services and NHS clinics enables wraparound care, allowing individuals to choose how and where they access psychosocial support in line with the matched care model.

Non-statutory HIV community services provide essential psychosocial support, including peer mentoring, advocacy, education, support groups, counselling and assistance with housing, immigration and benefits. These services have historically played a crucial role in the health and wellbeing of people living with HIV, addressing needs unmet by statutory services in a culturally competent manner [162, 163]. While statutory services should hold primary responsibility for psychosocial care, community services offer a unique, safe and accessible space that provides culturally informed support and empowerment.

There is a growing recognition of the need for ongoing supervision and support for volunteers within HIV community services to sustain and strengthen these interventions. The commissioning section of this standard further expands on the strong evidence for the effectiveness and economic benefits of psychological interventions in physical healthcare [32, 159, 160].



## Ensuring access to high-quality, integrated care

Creative approaches to service design are essential for sustainably addressing challenges related to mental health and service provision for people living with HIV. This requires the establishment of collaborative pathways that transcend organisational boundaries and adhere to core principles informed by the latest knowledge of HIV and psychological health. Services must be appropriately resourced and configured to ensure equitable access and meet the specific needs of people living with HIV, despite differences in healthcare planning and funding systems across England, Northern Ireland, Scotland and Wales.

These evidence-based Standards aim to guide the design, delivery, and commissioning of services, ensuring effective support that addresses the full range of health needs of people living with HIV. Their objective is to guarantee that all adults living with HIV in the UK receive consistent, high-quality, culturally competent and inclusive psychological, cognitive, and emotional support, regardless of location. The Standards are intended for a wide range of stakeholders, including healthcare providers, psychology practitioners, policymakers, commissioners and community organisations. They apply to services delivered by both specialist and non-specialist HIV services, in-house psychology departments and organisations across the statutory, third and private sectors.

The Standards are structured around eight key areas, which collectively provide a comprehensive vision for psychological support for people living with HIV. These areas are supported by a growing evidence base highlighting the complex relationship between HIV and psychological wellbeing, the mental health effects of stigma and structural inequalities faced by people living with HIV, and the need for specialised, culturally competent psychological support.

## **Guiding principles and policy drivers**

These Standards are informed by professional guidance, UK government policies and national reports that increasingly recognise the importance of psychological care in HIV management. They should be considered alongside evolving clinical guidelines, such as the BHIVA guidelines for routine investigation and monitoring, to ensure alignment with best practices. The BHIVA *Standards of Care for People Living with HIV* (2018) [164] highlight the need for comprehensive psychological support to address the emotional, mental, and cognitive wellbeing of people living with HIV.

Key government policies, including the *Five Year Forward View for Mental Health* [165] and the *NHS Long Term Plan* [166, 167], emphasise integrating mental and physical health services, particularly for long-term conditions like HIV. Mental Health and Wellbeing Strategies for Scotland [168] and Wales [169] advocate a holistic, person-centred approach that recognises health inequalities and social determinants of health. The Core20PLUS5 framework [170] prioritises mental health and seeks to reduce disparities among marginalised groups.

National reports reinforce the need for specialist mental health services. The *Missing Link: HIV and Mental Health* report [171] called for a national strategy, while the National AIDS Trust report 'HIV and mental health: improving generic NHS talking therapy services for people living with HIV in England' (2021) [16] recommended embedding mental health



professionals in all HIV clinic teams. The *HIV Action Plans* for England, Northern Ireland, Scotland, and Wales [172-175] aim to reduce stigma, integrate mental health services, and achieve zero new transmissions by 2030. England's *Towards Zero: The HIV Action Plan for England 2022 to 2025* [172] commits to ending new HIV acquisitions, late-stage diagnoses, and HIV-related deaths by 2030.

The NHS 2024 HIV Service Specification [176] supports integrated care that addresses the socio-cultural, psychological, and neurocognitive needs of people living with HIV. All UK nations have reached the UNAIDS 90-90-90 target, with England also meeting the 95-95-95 target, while Northern Ireland, Scotland and Wales are progressing towards it [2-5].

#### **Purpose of the Standards**

Developed by the British HIV Association (BHIVA), these Standards provide evidence-based guidelines for psychological support in HIV care, ensuring accessibility, quality, and integration. The key aims are to:

- Ensure consistency and quality of care by establishing clear guidelines to minimise service variability and maintain high standards nationwide.
- Integrate care services through collaboration among healthcare professionals, mental health practitioners, and peer support networks to comprehensively address both physical and mental health needs.
- Address inequities and stigma by reducing disparities in access to psychological support, particularly for marginalised groups, and tackling HIV and mental health stigma.
- Promote continuous improvement by providing a framework for regular evaluation and adaptation of psychological services to meet the changing needs of people living with HIV.

By embedding psychological support within HIV care, these Standards help ensure all adults living with HIV receive the support needed to thrive. They contribute to the goal of ending new HIV transmissions by 2030 while fostering a culture of inclusivity, compassion, and excellence in care.



# Commissioning psychological services for people living with HIV

#### Introduction

Given the high prevalence of psychological distress and mental health issues among people living with HIV and the diverse and intersecting needs of this population, HIV care provision must evolve to address the complexities of an ever-changing clinical landscape [20, 41, 42, 164]. Evidence of these needs directly impacts the development of BHIVA clinical guidelines which aim to promote excellence in HIV care through the systematic review of evidence [164]. The implementation of such guidelines in healthcare settings is auditable through the use of performance measures that drive quality improvement. The Standards should be viewed in conjunction with evolving clinical guidelines which have relevance to psychological and cognitive health.

The HIV community and clinicians call for psychological support to be a non-negotiable aspect of HIV, as reflected by the BHIVA Standards of Care and the NHS HIV service specification [176, 164, 177, 178]. People living with HIV hold status-sharing worries and anxieties, often based on adverse incidents connected to HIV-related stigma and discrimination in healthcare settings and the inability of generic mental health services to consistently provide culturally competent, HIV-sensitive support [36, 51, 179, 180]. In light of this, there is a strong case for specialist HIV psychological care embedded within the HIV multidisciplinary team (MDT). Multidisciplinary approaches are well established as the most effective way to tailor services to meet complex biopsychosocial needs [161, 181].

## Why psychological support is required

The evidence demonstrating reciprocal and interrelating connections between physical and mental health is so robust that it is sufficient basis for policy formation [182]. The evidence demonstrating the reciprocal and interrelated connections between physical and mental health is so strong that it provides a sufficient basis for policy development [182]. Some examples of the risks of neglecting mental and cognitive health needs, compared to the benefits of specialist psychological care, are outlined in Table 1.



Table 1: Risks of neglecting mental and cognitive health needs vs. benefits of specialist psychological care for people living with HIV

Implications of unmet mental and
cognitive health needs in HIV care

Poor psychological health, wellbeing and quality of life [14, 183, 184]

Increased death by suicide [185]

Greater adherence difficulties and disengagement from care [183, 186]

Poor physical health outcomes, with risk rising as psychological distress worsens [14, 183, 186]

Higher risk of severe health deterioration and hospitalisation [182, 183, 186]

Worsened access inequity to mental health care due to stigma-related barriers [36, 183, 186]

Increased risk of HIV transmission [183, 186]

More frequent medical and nursing appointments due to unmanaged distress and related health concerns [187]

Non-mental health clinical staff managing complex psychological needs, risking secondary trauma, burnout and absence [67, 188, 189] increased service costs due to poor health outcomes, more clinical contacts, outreach efforts and inpatient admissions [14]

## Benefits of integrated psychology provision in HIV care

Concurrent treatment of physical and mental health improves outcomes [22, 183, 190, 191]

Specialist, culturally competent HIV-sensitive psychological interventions improve engagement and outcomes [36, 183, 190, 192, 193]

Early psychological assessment and intervention prevent escalation of needs [194, 195]

Flexible psychological services provide consistent support and consultation to the MDT, especially for complex needs [22, 159, 160, 183]

Addresses health inequalities by increasing support access for those with complex needs and marginalised communities within a trusted care team [36, 183, 190, 192, 193]

Reduces HIV acquisition risk [183, 186]

Builds relationships with people living with HIV, using psychological formulations to inform all aspects of care and repeated access to interventions [159, 160]

Facilitates collaboration with HIV community services and engagement with people living with HIV [186, 187]

Develops relationships between psychology and HIV clinicians, enabling wrap-around, collaborative, person-centred care [186, 190, 192, 193]

Psychological practitioners provide training and supervision to HIV MDT staff to:

- Deliver psychologically informed care [66, 196]
- Reduce risks of secondary trauma and burnout [196]



To see tangible examples of the benefits of specialist HIV psychology integrated into the HIV MDT, please refer to good practice examples E–G and N.

## **Cost-effectiveness of psychological support**

Addressing the interacting and mutually exacerbating effects of coexisting physical and mental health problems is more costly for the NHS [197], increasing healthcare costs by at least 45% for each individual managing a long-term health condition and psychological distress [14, 32]. The stigma and discrimination experienced by people living with HIV add further complexity and costs [198]. Therefore, providing integrated care that addresses psychological needs within MDT care delivery can help to reduce these costs. There is a well-established evidence base supporting the cost-effectiveness of psychological interventions for the health and wellbeing of people with long-term conditions. Downstream cost benefits include improved adherence, fewer inpatient admissions, reduced pressure on emergency mental health services and enhanced self-management by service users, resulting in less clinic time utilisation [14, 32, 181, 183, 186, 187]

## Commissioning priorities: guidance for NHS psychology provision

The NHS Long Term Plan (2019) [166] pledged to allocate a larger share of the NHS budget to mental health services. The most pragmatic and cost-effective way to use this funding to deliver culturally sensitive and psychologically informed HIV care is to commission specialist HIV psychological practitioners embedded within the HIV multidisciplinary team (MDT) [14, 66, 159, 160, 183, 191]. If people living with HIV are not given the option of specialist psychological support, health inequities are likely to persist due to stigma acting as a barrier to accessing generic services [36, 183].

Where in-house HIV psychological support is not commissioned, steps must be taken to ensure that local pathways to mental health support are clearly defined and that these services can provide HIV-sensitive care. Commissioners must ensure that local services commit to the HIV Confident charter [199] and that practitioners complete the NHS elearning module [200]. Efforts should be made to foster links between HIV and other relevant services to address the often-complex needs of people living with HIV (see good practice example K). This could be achieved through:

- Utilising existing frameworks such as NHS talking therapies
- Mandating high quality HIV-education for all practitioners
- Adding HIV to the Long-Term Conditions model [16]
- Actively creating local care relationships between HIV clinics and generic mental health support
- Recognising and addressing challenges relating to geographical disparities (e.g. complexities around regional service delivery; underserved rural locations).



Although educating generic services may support HIV-sensitive care, it will not resolve the issue of HIV clinicians managing high levels of trauma and psychological complexity without appropriate support (e.g., supervision, reflective practice, joint working).

As commissioning landscapes evolve, those responsible for HIV care must prioritise mental health needs to ensure parity of esteem between physical and mental health [14]. When different bodies are responsible for commissioning medical aspects of HIV care and psychological support, there is a risk that the psychological needs of people living with HIV will fall into a commissioning gap, meaning culturally competent services may not be funded or delivered.

The small local organisations were life savers but if you're not funded by councils or grants, you've got no chance. You won't survive.

Stuart

Given the current transition towards devolving specialist service provision to integrated care boards, with a varied picture of national and local commissioning, clear lines of accountability must be established in relation to HIV psychological care. It is essential to understand the diverse needs of each local HIV population and adhere to care standards to inform commissioning decisions. Service managers must be aware of local arrangements and negotiate funding accordingly.

Commissioners can use these Standards at various points in their commissioning cycle:

- **Setting up services:** to specify the psychological support services should provide; to understand how services plan to meet these needs; to recognise service models that offer value for money while maintaining adequate quality and range of service; to ensure there is sufficient leadership and supervision for service providers.
- Monitoring services: to ensure services are providing appropriate support; to check
  if services are meeting specified needs; to choose relevant key performance
  indicators; to collect feedback from people living with HIV; to identify unmet needs.
- Reviewing services: to gather feedback and measure satisfaction among people
  living with HIV; to identify outcomes and success indicators related to engagement,
  physical and mental health outcomes, quality of life and value for money.

Additionally, commissioners and strategic leaders responsible for suicide prevention should establish systems for gathering and sharing data with sexual health/HIV services to ensure that deaths by suicide within the HIV population are not hidden.

## **Commissioning of non-NHS services**

HIV community support services are central and essential to the mental health and wellbeing of many people living with HIV. They work alongside and often collaboratively with NHS clinics and can provide a wide range of psychosocial support services to address needs that can left unmet by statutory systems [131, 162, 163]. Although community services should not be obliged to meet core needs, in reality they often do, with some perhaps preferring to access support this way. Given that addressing psychosocial needs has a beneficial impact



on both psychological wellbeing and physical health outcomes [201, 202], these services should be considered as a central to HIV care planning and commissioned accordingly.

Substantive funding is required to enable community services provide an ongoing accessible space and wraparound support for people living with HIV. This can relieve pressure from statutory services and will be cost effective in terms of preventing the escalation of distress and the associated impact on physical health and wellbeing [203, 204]. It is important to plan and invest in community provision that enhances the psychosocial offer for people living with HIV, as this enables the evaluation and development of support and embedding personcentred and peer-led approaches. Insecure funding can place stress on community services and prevent the continuity and flow of support required for the HIV population, who are managing ongoing issues and stressors [204].

Peer support and peer mentoring need to be properly resourced and managed, with appropriate organisational procedures (e.g. GDPR, risk assessments, policies on confidentiality, lone working etc.) and have robust monitoring and evaluation processes, whilst peer supporters should be DBS (Disclosure and Barring Service) checked and have the appropriate training to work with vulnerable adults [205].

## Models of NHS psychological support provision

It is not feasible to prescribe a 'one size fits all' model as local needs will vary due to a range of factors. However, extrapolating from other long-term condition fields can be helpful. For example, the *UK Renal Psychosocial Workforce Report* (2018) [206] suggested a need for one whole-time equivalent (WTE) psychological practitioner per 600 people with renal conditions, based on 25% requiring psychologist involvement. The psychological needs of people living with HIV are considerably more complex. A conservative estimate, based on 35% of people living with HIV needing referral for Level 3 or 4 psychological needs [20, 41, 42], suggests a requirement for 1 WTE psychological practitioner per 430 people living with HIV. On this basis, Table 2 offers a framework to guide commissioning decisions.

If the government and funders look at it as a public health outcome, and that we contribute to the economy, to society. If they take care of us then we are taking care of our extended communities.

Fungai



Table 2: Examples of psychological service provision from inadequate to gold standard

Service level indicator	Psychological practitioner provision (based on a patient population of 2000)	Limitations to care	Implications for meeting care Standards and cost
RED	No specialist psychological input into HIV service (No up-front cost)	Lack of culturally competent psychological assessment and intervention; HIV clinicians unsupported in managing complex psychological needs; full reliance on generic mental health services, worsening health inequalities	Unable to meet psychological care Standards; increased costs due to morbidity and mortality
AMBER	1.0 WTE psychological practitioner (Band 8b) (Cost as per agenda for change including oncosts)	Focus primarily on direct psychological assessment and intervention, with limited capacity for broader roles (e.g. teaching, staff support); unlikely to provide timely interventions; limited collaboration with HIV community; minimal capacity for audit, evaluation and research; complex aspects of NHS service management beyond this banding's experience	Partially meets psychological care Standards; potential ongoing costs due to unmet mental health needs and limited support for HIV clinical staff
GREEN	0.6 WTE Consultant/Lead Psychological Practitioner (Band 8c), 0.8 WTE Support Lead Practitioner, 2.6 WTE Psychological Practitioners (Band 7/8a) (Cost as per agenda for change including oncosts)	Well-resourced service capable of delivering all aspects of clinical care as well as collaborating with HIV third sector organisations, to meet all aspects of the matched care model in most situations	Fully meets psychological care Standards; long- term cost savings



#### The matched care model

A key enhancement of the 2025 Standards is the adoption of a **matched care model** (replacing the previous *stepped* care model) to allow a more tailored and person-centred approach [207]. This reflects a recent paradigm shift in NICE guidance for depression (2022; p113) [208]. Both models aim to deliver and monitor interventions so that the most effective and least intrusive and least resource intensive are delivered first:

- **Stepped care:** people who do not benefit from an initial intervention can 'step up' to more intensive treatments as needed (and 'step down' as their recovery progresses).
- Matched care: Meeting the person where they are, without the need for starting at a
  particular step. Careful assessment considers other factors including an individual's
  needs, previous experience of intervention and their preference and choice.

The new model (Figure 1) combines Figures 1 and 2 from the 2011 Standards. It centralises and incorporates more clearly peer support and self-management, which previously could have been misinterpreted as being ancillary or peripheral (see good practice examples A–C) Furthermore, the model focuses not on specific staffing professions, but the person living with HIV's needs and the nature of interventions required at each level (assuming appropriate training, qualifications, competencies and supervision to deliver these).

It is not possible to cover every possible intervention in either the matched care model or the Standards themselves, as these will vary according to need and local availability. It is therefore important to ensure the person's needs are matched against the model via an assessment suitable to level of need. This assessment and formulation will inform the intervention.



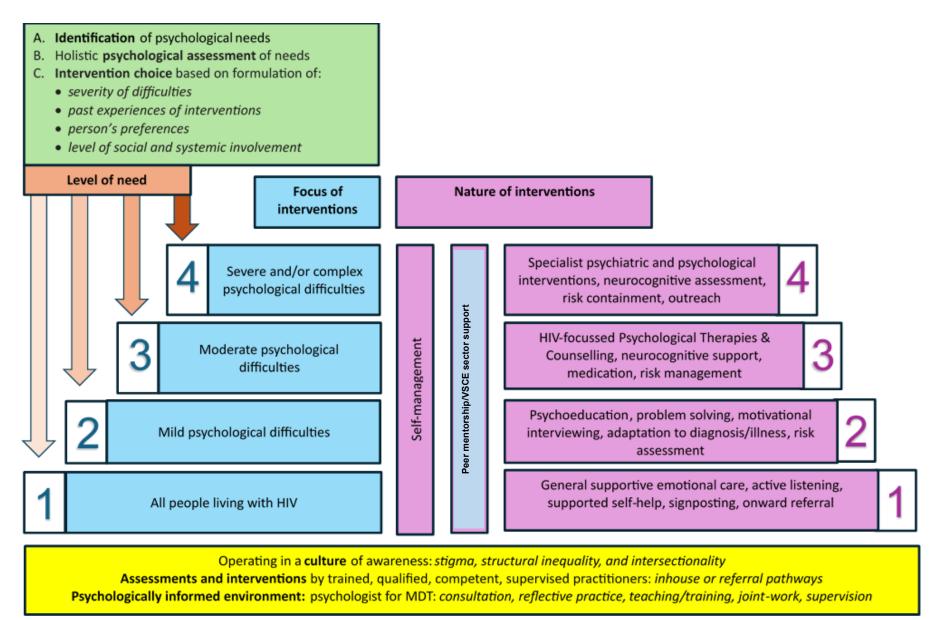


Figure 1: Matched care model of psychological support for people living with HIV



## Psychological needs identification

Initial identification of psychological difficulties for people living with HIV is likely to be performed by non-mental health specialists in medical and nursing clinics, who will benefit from supervision and consultation in this process with psychological practitioners. This may arise from standardised screening, or the clinician or individual identifying psychological need within their consultation (which may have been convened with this focus or initially have been focussed upon something else). Some services may also offer people living with HIV the option to directly self-refer for psychological assessment and support.

## Psychological screening and assessment

Conversations and assessments around mental health and wellbeing should occur regularly within a clinical culture where staff and people living with HIV understand that talking about psychological difficulties is appropriate and welcome. Each consultation should be an opportunity to check in regarding psychological wellbeing and existing clinical relationships can be a vehicle to identify issues that could potentially go under the radar (see good practice example D). Initial explorations of psychological issues may need to be augmented with screening measures (see Appendix D) and /or referral for more specialist assessments depending on the issues and the competencies of the assessing clinician.

For full triage to decipher the appropriate level of intervention, a holistic psychological needs assessment must take place. This should be by, or in consultation/supervision with, a psychological practitioner. Each assessment will vary depending upon the individual and their difficulties and should be sensitive to the complexity of issues and diversity of the individual and their socio-cultural context.

Too often our consultants are the only ones that we have a 'safe relationship with' to discuss things and if we are not prompted to explore our wellbeing beyond our viral load, we will continue to just survive, when we have a potential to really thrive.

Meriel

Table 3 gives examples of types of difficulties that might correspond with different levels of need. We have deliberately avoided a diagnostic/labelling approach, to encourage formulation of psychological difficulties on an individual level.



Table 3: Levels of psychological need

el 1	Everyone	Normal ongoing reactions to living with HIV and/or expressions of concern about a specific issue(s), but no marked distress
Level	living with HIV	e.g. voicing of common everyday worries or frustrations of living with HIV
Level 2	Mild psychological difficulties	Mild display of distress with limited impact on everyday function. May be around a specific health-related issue or transition point of living with HIV
ľ		e.g. new treatment, sharing diagnosis etc.
el 3	Moderate	Moderate display of distress impacting a person's ability to live their life in the way they wish to
Level	psychological difficulties	e.g. anxiety, low mood, traumatic distress regarding a single incident, some memory/cognitive concerns
	Severe and/or	Considerable displays of distress
Level 4		e.g. complex/multiple trauma (persistent, often childhood trauma), high levels of social deprivation, interpersonal/relationship issues, different experiences of reality to others, persistent medication or care engagement issues, significant memory/cognitive issues.

#### Intervention choice

The intervention choice should be matched to the person living with HIV based upon the formulation of:

- The severity of their difficulties: greater severity requiring a higher degree of intervention
- Past experiences of interventions: positive/negative informing what might help or not again
- The person's preferences: presuming capacity, availability and that it is not contraindicated
- The level of social and systemic involvement: so that individuals are not pathologised and any social inequality or injustice may be systemically challenged.

Within this, self-management and peer support should always be considered. Whilst ideally most resources and interventions would be provided within the HIV clinic (see good practice examples E, F and N), it is recognised that due to staffing levels and/or skill mix that some individuals may need to access specific referral pathways outside of their HIV clinic. People



living with HIV have reported mixed experiences of this [36]. Therefore, when onward referral is required, NHS England (2024) have developed a relevant, free e-learning module *Breaking barriers in HIV care* [200] that can be sent with the referral (as long as there is consent to share status) to provide practitioners with required HIV knowledge to improve cultural competency.

## Psychologically informed environment

Although the model suggests that psychological needs are met by suitably qualified and specialist practitioners, non-mental health clinicians will still be working with people at every level of need in these and other aspects of their HIV care. This reinforces the requirement for psychological practitioners to be embedded within the HIV multidisciplinary team, so that support can be provided to deliver psychologically informed care through activities such as consultation, reflective practice, teaching, training, supervision and joint working (see good practice examples H–J).

I've been very fortunate and seen the same clinician, right from the beginning. She's been very consistent and a wonderful nurse specialist. She actually went beyond emotionally. She was very supportive and available. I could text her – she made a big difference, actually. Eve

## Service development

Clinics that wish to develop business cases for within-service psychological roles can refer to the commissioning section (intro) and a suggested business case template in Appendix C In lieu of this, creative solutions may require operationalisation that are sensitive to different organisational and staff remits, budgets, job plans and data sharing agreements, to provide the best service for people living with HIV (see good practice examples B, K and L)



# Standard 1: Promotion of mental health and psychological wellbeing

## **Summary**

People living with HIV should receive care which promotes their emotional, cognitive, psychological and behavioural wellbeing and that is sensitive to the unique aspects of living with HIV.

#### Recommendations

- **1.1** Psychological wellbeing on the agenda: people living with HIV should have the opportunity to discuss their psychological wellbeing during all clinical appointments.
- **1.2 HIV-sensitive care:** people living with HIV should receive confidential, non-stigmatising and culturally competent care informed by the unique HIV-related factors affecting psychological wellbeing. All verbal and written communications must use people-first terminology.
- 1.3 Informed psychological wellbeing: people living with HIV should receive information and resources to support their psychological wellbeing, along with access to peer support and patient representatives during health and social care interactions.

#### Rationale

People living with HIV face a higher burden of mental health challenges due to various intersecting biopsychosocial factors, including HIV stigma [20, 40-42]. Psychological difficulties experienced include anxiety, depression, post-traumatic stress disorder, adjustment and coping issues, medication adherence barriers, sexual problems, suicidal thoughts and neurocognitive issues. Marginalised demographic groups, as well as individuals with prior trauma such as adverse childhood experiences (ACEs) or the experience of fleeing unsafe conditions to seek asylum, may have an increased risk of psychological distress [47, 58, 59].

I didn't want a clinical setting; I just wanted to sit with a coffee and a biscuit and just have a chat.... You don't have to mention HIV, you just chit chat, you're just people.

Stuart

Stigmatisation can occur with any healthcare professional but may be more prevalent among those not specialising in HIV care [36, 51, 126]. Exploratory clinical conversations are crucial to identify mental health difficulties [20, 40-42, 66, 209, 210]. However, people living with HIV often report that clinicians do not assess their psychological or cognitive wellbeing, potentially due to constraints like limited time, staff resources and training [19]. Without such assessments, opportunities to direct people living with HIV to relevant services for



assessment and intervention are missed, negatively affecting both mental and physical health outcomes (see Standard 5 for psychological assessment details).

Confidentiality is crucial for people living with HIV, as sharing their status without consent can cause significant psychological distress [51, 179]. Ensuring confidentiality is essential to encourage access to psychological care. While sharing an individual's status can help with the provision of appropriate support, it must always align with the needs and wishes of the person living with HIV. Agreements on confidentiality should be transparent and explicit to minimise anxiety and enhance engagement [211, 212].

All verbal and written communications must use people-first language, as stigma and blame perpetuated by incorrect terminology can harm psychological wellbeing. Using respectful language aligns with the highest attainable standards of health, reflecting the fundamental human rights of people living with HIV [1].

It is possible to look at the needs of people living with HIV by stripping things back, trying to meet people where they are, and finding something for them that is going to be their lifeline for as long as they need it.

Fungai

Promoting psychological wellbeing is most effective when done in partnership with community and clinical networks. National HIV care and advocacy organisations, commissioners, HIV communities and clinical services share the responsibility of maintaining awareness of the psychological needs of people living with HIV by providing information about local support pathways and other accredited resources, such as online materials from national bodies and community support services. Account should be taken of cultural, language and literacy needs, to ensure all people living with HIV have equitable access to information. Contact with patient representatives and/or peer support provides a beneficial way to convey information and may also facilitate access to further psychological support.

People living with HIV have individual preferences for where they discuss their mental health and wellbeing needs, though these choices may be restricted by geographical disparities in service availability [213, 214]. Open communication and collaboration among service commissioners, peer support providers and community and clinical services are crucial for prioritising psychological wellbeing and promoting access to relevant services (see good practice examples B–D and G).



## Standard 2: Comprehensive psychological support services

#### **Summary**

People living with HIV should have access to a range of psychological support services appropriate to their needs.

#### Recommendations

- **2.1 Psychological support leads:** HIV services should have a designated clinical lead for psychology embedded in HIV leadership teams to oversee all aspects of psychologically informed care.
- **2.2 Psychological assessment:** assessment (i.e. in-clinic conversations, psychological and cognitive screening and in-depth psychological assessment) should be inclusive, present throughout all aspects of HIV care and appropriate for diverse needs.
- 2.3 Matched care model: the matched care model should guide all service and care planning and access to culturally competent psychological support at Levels 1 through 4.
- 2.4 Access to interventions: clear local pathways to psychological support should follow the matched care model and communicated to HIV MDTs. These should prioritise in-house HIV specialist interventions and HIV third sector organisation support. Non-HIV specialist services must meet the needs of people living with HIV effectively.
- **2.5 Timely access:** interventions should be delivered promptly according to need, with support plans communicated as soon as the need is identified.
  - Non-urgent Level 1 and 2 needs should be responded to immediately with compassionate, context-sensitive communication and prompt signposting.
  - Non-urgent Level 3 and 4 needs requiring specialist support should have a referral-to-treatment time of no longer than 18 weeks, as per national guidelines.
  - Urgent Level 4 needs should be referred immediately to emergency mental health services and assessed or triaged in accordance with NICE and other national guidelines.

#### Rationale

While some people living with HIV cope well with their diagnosis, many are more likely to experience trauma, psychological distress and mental health issues due to intersecting

Eve



factors like stigma, discrimination and structural inequality [20, 40-42, 51, 58]. Psychological support plays a crucial role in treating mild or transient emotional distress, wellbeing and more severe problems such as depression, anxiety, trauma, or suicidal ideation [15, 66, 202, 215]. These issues can recur, escalate and significantly impact a person's ability to function in daily life and maintain relationships. This can lead to social isolation, mental health, and engagement in care and treatment, which subsequently impacts health outcomes [20, 51, 184].

Yes, so it was like telling me I'm too complex for therapy...it happens a lot, this lack of resource for dual diagnosis, or triple diagnosis...if you have addiction, eating disorder, mental health and HIV, no chance, I find that we all work in silos in the NHS.

Screening and assessment are vital for identifying psychological and cognitive needs, gaps in support and implementing appropriate interventions through the matched care model. The stepped, or matched care approach is widely used in mental health and when applied in physical health settings, benefits from in-house psychological leads to oversee its implementation [159, 208, 216].

Some aspects of stepped care have been implemented in HIV services where staff resources permit, usually in response to visible distress. However, routine screening for psychological and cognitive difficulties is often lacking, leading to unrecognised needs [213, 217]. Without proper assessment, there is no pathway to intervention, increasing the risk of persisting or worsening difficulties, with serious consequences for both physical and mental health and acquisition risk. Integrated physical and mental health services are the ideal care model, aligning with broader mental health policy and strategy [14, 159, 218].

Psychological support within the HIV team is recommended due to the importance of HIV-related cultural competence and psychologically informed care [36, 66, 196]. While this approach suits most people, some may prefer psychological support outside the HIV team and referrals to other specialties may be appropriate. HIV treatment providers and psychological support services should be aware of key times and events when peer support can be beneficial, such as at time of diagnosis / when informed of their diagnosis, starting/changing treatment, major illness and/or diagnosis of co-morbidity, starting/ending relationships, planning a family, pregnancy, moving from child to adult clinical care, key life events of aging, major life changes [205].

There are various ways to address the psychological and cognitive needs of people living with HIV, guided by person-centred care principles. Within the HIV clinical MDT, some practitioners may have Level 2 psychological skills training (see Appendix E) and others may be dual trained at Level 3 in therapeutic models like CBT or counselling. In-house clinical or counselling psychologists, psychotherapists and psychiatrists can provide Level 3 and 4 interventions, while clinical psychologists may also offer neuropsychological assessments and interventions [219]. HIV third sector organisations are also central to addressing psychological needs directly through services such as counselling, peer mentoring and support groups, and indirectly through provision which addresses social determinants of health, such as support with welfare benefits, housing or immigration issues [162, 163].



For HIV services lacking sufficient in-house psychological practitioners, where Level 3 and 4 referrals to generic psychological services are needed, directing staff to relevant training (see Appendix E) and obtaining consent for cross-service collaboration can be beneficial, especially for complex cases [190, 220]. Non-psychologist HIV MDT members provide care for people with needs at all four levels of the matched care model. Without in-house psychological support, delivering psychologically informed care is challenging, placing additional stress on clinicians in complex situations [121-225]. HIV community services offering peer support may also lack access to psychological practitioners for guidance with emotionally complex work, which could be alleviated by local arrangements with HIV specialist psychology leads.

It's important to look at what has gone before, all the experiences I've had before the diagnosis, and say what's the best for you and not have a one size fits all approach; that's vital.

David

Timely interventions are crucial, as delays can exacerbate psychological distress and physical deterioration [194]. Delayed access to psychological expertise increases pressure on MDTs to manage complex needs. The matched care model requires a prompt, multiprofessional and collaborative response to address the psychological needs of people living with HIV. In-house psychological services, appropriately staffed to meet the needs of the population, are best positioned to achieve referral-to-treatment times consistent with national guidelines (see commissioning section and Appendix C)

See NHS England Consultant-led treatment: right to start within 18 weeks for further guidance on referral to treatment waiting times and good practice examples A, C, F, G and N.



## Standard 3: Engagement of people living with HIV

## **Summary**

People living with HIV should be engaged in the planning, delivery and evaluation of psychological support services.

#### Recommendations

- **3.1 Co-production in service planning, development and evaluation**: People living with HIV should be engaged in the planning, delivery and evaluation of psychological support services:
  - Designing, redesigning and developing specialist HIV services.
  - Participating in evaluation activities to inform service management.
  - Co-developing outcome measures for psychological support services.
  - Shaping local and national HIV policy and research agendas.
- **3.2 Supporting co-production**: HIV specialist services should implement EDI policies and inclusive frameworks to ensure involvement from all communities affected by HIV. People living with HIV engaged in service improvement and delivery should be provided with supervision, training and opportunities to enhance their skills as needed.
- 3.3 Including the HIV community in service delivery: people living with HIV should play an active role in delivering HIV and specialist psychological support services through peer support, advice and advocacy. All HIV specialist services should either provide direct peer support or have established pathways to external providers to ensure access as needed.
- **3.4 Commissioning and remuneration**: HIV community organisations should be commissioned to support co-production and people living with HIV should receive remuneration for the work they carry out.

#### Rationale

People living with HIV offer uniquely valuable insights into the design, delivery and evaluation of services, including psychological support. Their meaningful involvement is crucial to programme effectiveness [222-226] and should be established before decision-making begins [227-229]. Flexible engagement methods and effective communication are essential for fostering involvement. All NHS services must now use patient and public engagement (PPE) approaches to improve quality, ensure accountability and increase cost-effectiveness [230, 231]. High levels of patient engagement can lead to structural changes in care processes and enhance outreach, with many reporting a sense of empowerment from their involvement [180, 227].



The involvement of people living with HIV and HIV third sector organisations is also endorsed by the internationally recognised Greater Involvement of People Living with HIV (GIPA) principle, which aims to uphold their rights, including self-determination and participation in decisions that affect their lives [232]. Creating safe, respectful spaces with realistic goals and robust evaluation is essential [230, 231, 233]. Addressing payment processes is key to ensuring ethical participation [226, 231].

Next thing is it's (vaccine access) being debated on TV in Parliament! That was because of us, because of my community forum. We are a voice, we did that. We are still doing it; I love the platform...

Stuart

Peer support services are a vital aspect of engagement (see also Standard 3), offering emotional support, advice, advocacy, information, workshops, forums and courses that benefit service users, peer support workers and clinic staff [222-224]. It is an important complement to statutory healthcare services which benefits both people helped and peers themselves [234]. Given the complexity and emotional labour involved with peer mentoring, psychologically informed training and ongoing supervision are essential to safeguard both the provider and recipient of the intervention (221, 205).

Proper representation requires work, I get it's not easy, you need to invite people, support them with a seat at the table, make room, encourage, train, reimburse, value. It's uncomfortable for people who are used to hierarchy and power.

Meriel

HIV-specific patient-reported outcome measures (PROMs) provide insights into how people living with HIV perceive their health and the impact of treatments or lifestyle changes on their quality of life. PROMs or patient-reported experience measures (PREMs) should be developed and agreed upon with people living with HIV to assess service quality, rather than relying on customer satisfaction measures [228]. These measures should evaluate factors such as access, communication, interaction with professionals, coordination of care, respect for privacy and dignity, information on mental health and wellbeing, meaningful involvement in decisions and overall experience (see also Standard 8 and good practice examples B, C and F).



## Standard 4: Support at the time of diagnosis

## **Summary**

People living with HIV should have timely access to information and appropriate emotional support following the diagnosis of HIV.

#### Recommendations

- 4.1 Support at the time of diagnosis: people living with HIV should receive appropriate psychological and emotional support following their diagnosis. In healthcare and community settings, the person delivering the diagnosis should offer emotional support, collaborate on a plan of care which includes addressing immediate psychological needs and ensure appropriate follow-up. All practitioners delivering results should be culturally competent, well-informed and compassionate.
- **4.2 Information at the time of diagnosis:** self-testing kits, healthcare settings and community testing services should provide up-to-date written information on HIV and signposting to reputable online resources. Healthcare and community practitioners should also provide high quality verbal information along with written materials.
- 4.3 Psychological support following diagnosis: all people newly diagnosed with HIV should have assessment of psychological, emotional and cognitive wellbeing, using screening tools if needed. Any referral for psychological support should be based on the matched care model. Local policies and pathways for post-diagnosis psychological support and referral must be in place. Urgent needs identified through clinical conversations should lead to immediate referrals.

## **Rationale**

When receiving an HIV-positive result, people may experience significant emotional reactions (43). Support must be provided to individuals around the time of diagnosis to help them navigate the weeks ahead. This should include arranging a follow-up clinic appointment, providing information on how to access psychological support, and signposting to HIV third-sector charities. All practitioners delivering test results and emotional support should be competent to do so and have access to relevant training and professional support (see Standard 6). Information on HIV and psychological support should be provided in individuals' preferred mode, which could include online resources, written materials, or verbal explanations. Accessibility needs must be accounted for.

So, having someone at the point of diagnosis to actually say, this is what it is, it doesn't have to be A, B and C; it can be D, E and F and that's the really important part of reframing and understanding what this can be for them.

David



Positive messaging is crucial and a clear agreed plan for the next point of contact should be established with the person accessing the service. Support must be provided in a culturally competent way that responds appropriately to different demographic groups, with referrals made where necessary. Everyone diagnosed with HIV and/or starting ART should be offered one-to-one support [235]. Clinics should have a clear pathway to peer support services and may wish to consider implementing an opt-out referral scheme for all patients as part of post-diagnosis support [223, 224, 236].

HIV testing occurs in various settings, including self-testing options available within the UK [237]. Testing sites should have clear referral pathways to specialist services, with an appointment offered within two weeks of diagnosis [167]. Consent must be carefully considered and practitioners delivering test results should be skilled in enhanced communication. Recognising people as individuals is essential, as the initial contact marks the beginning of a holistic care approach from diagnosis onward. Early communication and support significantly influence individuals' future engagement with HIV services and their overall journey with HIV [238].

Being diagnosed with HIV can be a particularly confusing, overwhelming and traumatising experience. Your life is about to change and there are many adjustments, experiences and knowledge gaps, which need to be carefully navigated. How the diagnosis is managed can set a template for the whole life trajectory of the person living with HIV; and support and guidance is essential to navigate this experience in as healthy a manner as possible. Shaun

Treatment guidelines recommend that all people living with HIV start antiretroviral therapy within 2–4 weeks of diagnosis [239]. Following diagnosis, factual and positive information, including U=U and living well, should be provided, along with addressing myths and misconceptions. It is important to recognise the psychological impact of starting treatment and the potential for information overload [240].

Shortly after diagnosis, discussions should include testing for relevant family members, children and sexual partners, supported by a skilled professional to ensure positive and accurate messaging [241]. If psychological needs are identified, referral to a specialist psychological practitioner may be necessary. Early access to psychological support from experts in HIV should be available following diagnosis (see good practice examples C and M).



## Standard 5: Identifying psychological support needs

## **Summary**

People living with HIV should have access to psychological screening as part of routine investigation and monitoring of HIV and cognitive screening as needed.

### Recommendations

## 5.1 Routine screening within HIV clinical settings:

- Clinicians should have exploratory conversations about psychological wellbeing at all routine, non-routine and walk-in appointments.
- Screening tools should be used if indicated, to assess for low mood/depression, anxiety, substance use, cognitive difficulties or PTSD.
- Suicide or self-harm risk should be explored through thorough needs-based assessment, using a risk formulation approach.
- Routine psychological screening should take place at least once per year.
- **Additional screening:** people living with HIV should have access to screening following events that are known to trigger or exacerbate psychological distress or cognitive difficulties.
- **Referral following screening:** clear, inclusive pathways for further assessment to a suitably competent practitioner must be in place for those whose screen suggests significant difficulties.

### Rationale

Many individuals adjust well to living with HIV and require minimal specialist psychological support. The matched care model [107] suggests that most people can navigate the initial adjustment period through lower-level support, such as active listening and guidance toward self-help and peer support. However, some may encounter difficulties or struggle to seek or access additional support.

Psychological distress and mental health difficulties in people living with HIV are often under-recognised by providers [40] and sometimes under-reported by individuals [51, 242]. To address this, services should implement a screening process to identify potential psychological support needs [23]. Screening should be tailored to the individual and context, starting with open-ended questions like 'How are you feeling generally?' and followed up with standardised tools (see Appendix D) if needed to determine whether a referral for more in-depth assessment by a psychological professional is necessary. It is important to distinguish between both types of screening and formal psychological assessment, which involves a comprehensive evaluation to collaboratively formulate a person's psychological issues and care plan.

Screening alone is insufficient to improve outcomes; it must be part of an ongoing care framework provided by staff with appropriate competencies [243] (see Standard 6).



Screening is designed to be broad and general, identifying the need for further assessment to determine if specialist support is required. While screening can be highly sensitive, it may lack specificity and, if used solely for diagnostic purposes, could pathologise normal human reactions and adjustment processes. Both open and standardised screening for psychological difficulties and risk should follow trauma-informed care principles to prevent further stigmatisation of individuals already facing HIV-related stigma (see Standard 1). Gathering basic information on current biopsychosocial circumstances, history and previous psychological distress or mental health service use can provide essential context during the initial screening process.

We say 'fine' because that's what we think the clinician wants to hear. If noone prods a bit more..., by being asked are you really okay, you can really tell me what's going on, and then we will talk. Angelina

Early detection and treatment of psychological difficulties in people with long-term health conditions can enhance health outcomes, improve psychological wellbeing and reduce the need for frequent and costly medical interventions [244, 245]. Routine clinical care should include screening for mental health issues and substance use, particularly for those with greater vulnerability. Standardised screening processes within services can help practitioners identify those needing further psychological assessment and support, effectively targeting limited resources, given the high prevalence of depression, psychological distress and trauma in people living with HIV.

Baseline screening for a range of common problems in people newly diagnosed with HIV enables the rapid identification of those who:

- Have pre-existing or current psychological difficulties that require prompt referral for further assessment
- May experience mental health deterioration due to difficulty adjusting to their diagnosis
- Could benefit from low-intensity interventions, such as Levels 1 and 2 of the matched care model
- Need referral for alcohol or substance misuse problems.

Certain screening tools can be administered by practitioners without formal mental health training or self-administered, depending on language skills and cognitive abilities. Screening can occur in various settings, from HIV clinics to community locations. However, individuals with cognitive impairments, learning disabilities, language or communication needs, sensory or neurodiversity issues, or significant post-traumatic stress may require screening by specialists. This should be assessed on a case-by-case basis, ensuring it does not create a barrier to screening [246-249].

Recent evidence indicates that although people living with HIV do report cognitive problems, they are often likely to be related to issues other than HIV, such as mental health issues, alcohol and substance use or other historical or current central nervous system or neurological conditions [79, 82, 250]. As a result of this, routine screening is not



recommended [250, 251]. However, concerns about cognitive problems remain highly salient for the HV community and anxiety can be assuaged by screening, with no perceived downside [252]. Therefore, exploratory conversations relating to cognitive issues should be held alongside those about psychological difficulties, as part of routine monitoring. Quick screening methods, including brief questions can help identify the need for further assessment. Screening tools should be suitable for the specific population and non-HIV specialists, such as general practitioners, should know that general cognitive screening tools may not be appropriate for people living with HIV (see Appendix D).

Psychological difficulties are more common in people living with chronic health conditions compared to the general population. People living with HIV should be re-screened at points known to trigger or worsen mental distress. These triggers may include:

- Changes in physical health
- Starting or changing treatment
- Switching treatment centres, transitioning from child to adult services or reengaging with care
- Periods of non-attendance or loss of contact with the treatment centre
- When antiretroviral treatment fails
- Inconsistent adherence
- Significant medication side effects
- Co-infections (e.g., hepatitis B/C, tuberculosis)
- Major psychosocial changes/key life events
- Distressing social issues (e.g., immigration difficulties)
- Experiences of stigma, violence, or abuse
- Bereavement, relationship, or family problems, including those related to children's HIV status.

When no trigger points are evident, conversations relating to psychological and cognitive issues should still be part of routine monitoring for people living with HIV, with psychological screening conducted at least annually.

Asking what's important to you, it could be my faith, good sex, or pursuing the career I had before diagnosis. We are all different with our answers but we all need to feel it's okay to share our needs and explore our options.

Meriel

If screening indicates significant psychological or cognitive difficulties, a prompt referral to a qualified specialist for a more in-depth assessment should be made. The outcome of this assessment should facilitate a collaboratively developed treatment plan aligned with the matched care model and NICE guidelines.



For those whose screening shows a lower level of need, signposting to or providing low-intensity support should be available. This may include psychoeducation (information on the causes and maintaining factors of current difficulties and suggested coping strategies), peer support, self-help and community resources (see good practice examples D, E and G).



## Standard 6: Competence to provide psychological support

## Summary

People living with HIV-should have their psychological support provided by competent practitioners.

### Recommendations

- 6.1 Competence to provide psychological support: psychological support should be provided by trained practitioners with proven competencies (aligned with the matched care model) in both their specialism and HIV. In-house specialists working with HIV MDTs are essential for optimal care. Peer support workers should meet the Standards for Peer Support. In non-specialist settings, practitioners must gain a thorough understanding of HIV through training, CPD and collaboration with HIV experts. Practitioners at all levels of the matched care model must use people-first language.
- 6.2 Maintenance and assessment of competence: all practitioners providing assessments and interventions should maintain their psychological and HIV-specific competence through CPD, reflective practice and receiving proactive supervision. Individuals practising at all levels of the matched care model have an ongoing responsibility to maintain competence, supported by their employing organisation. Competence should be assessed both formatively and summatively through ongoing supervision, personal development reviews, observation of practice and verbal feedback.
- 6.3 **Training:** specialist HIV psychological practitioners (matched care model Levels 3 and 4) must keep their HIV knowledge updated and should offer in-house training, supervision and CPD to Level 1 and 2 MDT members. Where there is no in-house psychology, HIV MDT members must access psychological skills training through validated and reputable training courses. In non-specialist settings, HIV champions should be appointed to ensure the communication of specialist knowledge and to challenge misinformation and stigma.

#### Rationale

All clinicians and third sector support workers engaging with people living with HIV must be psychologically supportive and deliver care responsive to psychosocial health and wellbeing needs. High-quality care requires the following minimum competencies, beyond the generic ones for their role [36, 40, 66, 79, 126, 128, 180, 200, 209, 211, 253-257]:

- Understanding the range of psychological issues related to living with HIV, including the impact of stigma, discrimination and trauma.
- Awareness of the People First Charter, the HIV Confident charter and the NHS training module Breaking Barriers in HIV Care.



- Knowledge of community services that enhance quality of life, such as third-sector organisations that provide access to specialist advice and support including the value of peer mentoring.
- Ability to understand intersections (such as race, sexuality, gender, disability, age, class, immigration status, income) that affect adjustment to diagnosis and ongoing management of health conditions.
- Awareness of cultural sensitivities, beliefs, faith and religion influencing adjustment to an HIV diagnosis and treatment.
- Familiarity with complex co-occurring issues, such as sexual health, substance use and chemsex.
- Trauma informed care skills recognising how HIV stigma can both arise from and intensify existing trauma; the impact of trauma and adverse childhood experiences (ACEs) on care engagement; the importance of harnessing resilience to support post-traumatic growth.
- Knowledge of the medical aspects of HIV, including acquisition, treatment regimens, side effects, adherence, U=U and pregnancy and family planning.
- Understanding of psychological barriers to adherence and strategies to address them from a trauma-informed perspective.
- Sensitivity to the elevated levels of i) intimate partner violence and ii) experiences of discrimination within the HIV population, and the factors which underpin this.
- Awareness of HIV-associated neurocognitive difficulties and their functional impact.
- Understanding of ethical and legal issues around 'reckless or intentional' HIV transmission and navigating these without contributing to stigma.
- Attention to confidentiality rights for people living with HIV, especially regarding healthcare providers or workplaces.

Competence in respectful communication is essential to providing non-stigmatising, culturally competent care. Practitioners at all levels of the matched care model must be trained in the use of people-first language to challenge terms that perpetuate stigma [1]. Knowledge of local HIV service options, access and referral criteria is crucial to limiting distress, supporting care engagement and improving health and wellbeing outcomes [36, 258, 259]. While psychological assessments and interventions should be conducted by qualified practitioners, psychological wellbeing should also be addressed in other care relationships, where competence in providing psychologically informed care is essential [66, 196]. Incorporating training, supervision and reflective practice into the roles of non-psychological practitioners enhances the care experience, reduces distress for people living with HIV and lowers the potential for secondary trauma for clinicians [221, 260].

Six weeks CBT just doesn't cut it for complex needs so specialist and trained providers are important.

Meriel



Regardless of their role or profession, all service providers and practitioners are responsible for ensuring competency in providing all levels of psychological support to people living with HIV. Practitioners must undergo formative and summative assessments to meet the Standards set by regulatory bodies and employers, ensuring fitness to practice according to their specific qualifications [205, 261, 262]. Additionally, due to the biopsychosocial complexity, high prevalence of trauma and associated mental health issues, all clinicians need further knowledge and skills to practice in psychologically safe and effective ways [66, 223, 221, 254].

Targeted training on trauma, mental health difficulties and issues related to living with HIV improves understanding of psychological issues, enhances communication skills and fosters better engagement with care, leading to improved health outcomes [66, 196, 220]. Trauma-informed care approaches have been shown to reduce distress and improve physical and mental health, while also protecting clinicians from secondary trauma [220, 221]. Clinicians in generic mental health services must also gain HIV-specific knowledge, as a lack of cultural competence can harm outcomes and reduce engagement with psychological support [36] (see Appendix E for suggested training courses).

There needs to be support – peer supporters need supervision. It's got to be formalised in that way – that's vital. There is a passion for ad hoc peer support, which I admire but everyone has to be safe…because there's more structure to peer support than an informal chat.

David

Psychological skills training for non-psychological practitioners (Levels 1 and 2) is most effective when delivered by in-house Level 3 and 4 specialist practitioners, supported by ongoing supervision and reflective practice [221]. The complex biopsychosocial issues faced by many people living with HIV require continuous formulation and a collaborative MDT approach [159, 160]. Collaboration between psychologically informed HIV clinical teams and specialist community support services fosters reciprocal learning, with wraparound care extending into the community to optimise health and psychological outcomes [164]. HIV champions within generic mental health services can address knowledge gaps, especially in areas with limited specialist services [263, 264].



## **Standard 7: Coordination of psychological support**

## **Summary**

People living with HIV should have access to appropriate psychological support services that are coordinated within a managed framework.

### Recommendations

- 7.1 Service design and provision: psychological support should be integrated into all phases of planning, design, delivery and evaluation for services accessed by people living with HIV. Commissioners, clinical leads, people living with HIV and other important stakeholders should work collaboratively to ensure high-quality, well-coordinated, inclusive psychological support across all levels of the matched care model.
- 7.2 Pathways of care: care pathways between HIV treatment providers and peer and psychological support services should be explicit, agreed upon by all partners and include self-referral options. Coordination across services should ensure that psychological support is available as needed, with a focus on transitions between services and throughout different life stages. Agreements must be in place regarding referral processes and data sharing.
- 7.3 Leadership and collaboration: psychological support must be underpinned by effective collaboration across organisational and professional boundaries, supported by clear, accountable leadership. Clinical leadership should come from Level 4 practitioners with HIV expertise, integrated into multidisciplinary HIV care teams, working closely with commissioners and local service leads. Knowledge, skills and resources should be shared across disciplines/services to ensure trauma-informed training, maintain competencies and advance interdisciplinary research on the health and wellbeing of people living with HIV.
- 7.4 Inclusivity and accessibility: Psychological services should be designed and coordinated in accordance with the diverse needs of people living with HIV. Psychological care pathways should be developed in a manner responsive to all ages gender identities, ethnicities and sexual orientations and language barriers to care and information addressed. Special attention should be given to those facing complex disadvantage. All referral mechanisms should be clear and accessible.

### Rationale

Effective coordination of high-quality psychological support services enhances the quality of life for people living with HIV [99], [168]. To achieve this, commissioners, clinical leads and other stakeholders must ensure that psychological support is given equal priority to other healthcare aspects and is fully integrated throughout the HIV diagnosis and treatment pathway, including inpatient, outpatient and community settings [22, 36].



Psychological support networks should provide culturally competent care across various intervention levels, from supportive signposting and peer support to specialised psychological and mental health services. Clear referral pathways should be established and coordinated between all key support services, including HIV care, mental health, maternity, neurology, addiction, autistic spectrum disorder, trauma, social and housing services, as well as relevant national and local third sector organisations.

Organisations involved in psychological support and HIV care should demonstrate their commitment to non-stigmatising, inclusive care by signing up to the People First Charter. This ensures alignment with the principles of dignity, respect, and equality for people living with HIV [1].

There's a wider conversation that's to do with joined up mental and social health care, and it's not something that we do very well. It's the third sector that props that up a lot.

David

Care pathways and services should be co-designed with service users, ensuring equity of access, cultural competence and smooth transitions across the lifespan. Regular reviews of local needs, demographic profiles, service demand, workforce capacity and demand-capacity gaps are essential to maintain high standards of accessible psychological support for all [265, 266].

Self-referral mechanisms should be established, particularly for accessing support at Levels 1 and 2 of the stepped care framework. These pathways must include clear information on confidentiality and be accessible throughout the diagnosis and treatment journey. Guidance for screening self-referrals at Levels 1 and 2 should be developed, enabling trained providers to triage referrals to the appropriate intervention pathway based on current support needs (see Standard 5). Clinical leads should maintain regular contact with all practitioners involved in the psychological support of people living with HIV, ensuring they receive relevant training, clinical supervision and shared learning opportunities. This will equip practitioners to provide trauma-informed psychological support at the appropriate level within their role (see Appendix E).

Specialist expertise in psychological issues for people living with HIV is essential for effective clinical leadership in psychological support services [164]. Clinical leads should create multidisciplinary and interagency forums to coordinate integrated care among stakeholders, including regular meetings for service planning, case discussions and training. These forums enhance care provision, support complex case management and promote a preventative approach that improves quality of life and ART adherence, aligning with the Towards Zero initiatives [4, 172, 173, 174]. This approach prioritises safety, experience, effectiveness, efficiency, timeliness and equity.

I think it's essential to work collaboratively across all disciplines when delivering care for people living with HIV. HIV and its impact does not operate in a silo.

Shaun



Commissioning plans must be guided by local strategies, up-to-date needs assessments and the expertise of frontline practitioners to ensure culturally competent, high-quality care. This should involve a thorough analysis of service demand, workforce capacity and the resources and skills of local providers. Workforce reviews should include succession planning to maintain specialist skills in HIV care. Additionally, developing research forums to expand the evidence base on the health and wellbeing of people living with HIV is crucial (see Standard 8). Monitoring and evaluating psychological support should measure safety, healthcare experience, clinical effectiveness, efficiency, timeliness and access equity (see good practice example N).



## Standard 8: Evidence-based practice

## **Summary**

All psychological assessments and interventions for people living with HIV should be based on the best available evidence.

#### Recommendations

- **8.1 Evidence-based assessment and interventions:** all psychological assessment and intervention methods used across the four levels of matched care should be selected and delivered according to the best available evidence of effectiveness.
- **8.2 HIV-appropriate assessment and intervention methods:** all psychological assessments and interventions should be selected based on their suitability for people living with HIV and/or other complex long-term conditions.
- 8.3 Contextualised assessment and intervention methods: all psychological assessment and interventions methods should account for contextual factors known to impact people living with HIV in the UK, such as biomedical, socio-cultural, environmental and economic influences.
- **B.4** Data collection, monitoring, and knowledge sharing: all providers of psychological services for people living with HIV should collect data (both qualitative and quantitative) for monitoring and evaluation. This data should be used to improve services, strengthen the evidence base for effective approaches, and drive innovation.

#### Rationale

The fields of medicine and applied psychology, including clinical and counselling psychology, are grounded in the scientist-practitioner model, which integrates clinical practice with theory and research, collectively known as the evidence base. This model upholds the principles of evidence-based practice, which combines research findings, clinical expertise, practical experience and the needs, goals and preferences of service users, to guide all stages of professional practice [261].

As research and theory continue to evolve, practitioners must regularly evaluate the evidence base to ensure it remains current, valid and relevant. Tools like Grading of Recommendations Assessment, Development and Evaluation (GRADE) [267] and GRADE-CERQual [268] provide structured frameworks for assessing and rating the quality of available evidence, which are crucial in the development of clinical care guidelines [269, 270]. However, these approaches have significant limitations, particularly in public health contexts [271, 272] as often fail to fully account for the complex multi-causal factors that underpin health [273]. Furthermore, there are persistent gaps in the evidence base for



people living with HIV arounds mental health, psychological interventions and variations between different demographic groups [274].

Incorporating clinical expertise and involving people living with HIV is hence especially important when the evidence base is limited or fragmented, such as in psychological assessments and interventions. In such instances, clinicians should consider different types of evidence:

- A. Stronger (or high-level) evidence relevant to the presenting difficulties of people living with HIV (e.g., NICE guidelines).
- B. Stronger evidence that applies to other long-term health conditions (e.g., NICE guidelines).
- C. Weaker evidence specific to people living with HIV, such as grey literature, clinical trials, or case studies.

When using non-HIV-specific or weaker evidence, it is critical to consider the strengths and limitations of applying such evidence and any necessary adaptations. As identifying the 'best available' evidence requires reviewing current literature, it is important for commissioners and clinicians (and non-clinicians delivering evidence-based practice) to stay up to date with emerging evidence as part of their continued professional development (CPD). Given the limited evidence for psychological assessments and interventions among people living with HIV, clinicians should consider sharing practice-based evidence with their colleagues, for example, through conference presentations and case reports.

Patient Reported Outcome Measures (PROMs) are increasingly used to demonstrate impact both in NHS and community settings but can be challenging to implement due to the burden of data collection, required changes in processes, organisational culture and IT infrastructure [275]. Ongoing research is assessing how PROMs can improve care quality as experienced by people living with HIV [276] thus service leaders and commissioners should regularly review emerging evidence and integrate this into evidence-based practices where appropriate.

There's so much research now isn't there, about the benefits of having longterm secure psychotherapy, in depth. There are financial benefits of investing in it, because there's such an impact on your physical wellbeing. Eve

There is a growing body of literature demonstrating the benefits of peer support and peer mentoring for people living with HIV [236, 277, 278] but gaps in this evidence remain around mental health improvement, implementation processes and cost-benefit analyses [180, 223, 224]. These gaps often stem from inconsistent measurement practices, highlighting a need for standardised outcome indicators and reporting methods [180] and increased recognition of the differential knowledge and practice that peer workers bring [279].

To ensure comprehensive, culturally competent and effective care, commissioners should make evidence-based decisions, evaluating interventions at all levels of the matched care model. Feedback from service users should be actively sought and sufficient resources



should be allocated to allow for the collection of robust data suitable for inclusion in the hierarchy of evidence-based medicine. Evidence from peer support and research from people living with HIV should be given greater weight in evidence-based practice, given its emerging importance and impact on biomedical and psychological outcomes.

There is an evidence base of good practice, which doesn't/ hasn't reached the standards and NICE guidelines, because they are not part of Randomised Control Trials or recognised by the experts compiling the research. This is not only in psychological support for people living with HIV but for many minoritised groups. Psychologists should not remain neutral on matters of social justice.

Meriel



## **Auditable indicators**

#### What is audit?

These Standards demonstrate a commitment to providing optimal care and enhancing the lives of individuals living with HIV. To achieve this goal, services should commit to assessing and monitoring their adherence to the standards, through participation in local and national audit. Clinical audit is defined as:

"A quality improvement process that seeks to improve patient care and outcomes through a systematic review against explicit criteria and the implementation of change." [293]

Clinical audit is a cyclical process to measure how well clinical processes functioning by measuring routine clinical practice against a set 'criterion' or 'indicators'. The audit process involves a number of steps as shown in Figure 2.

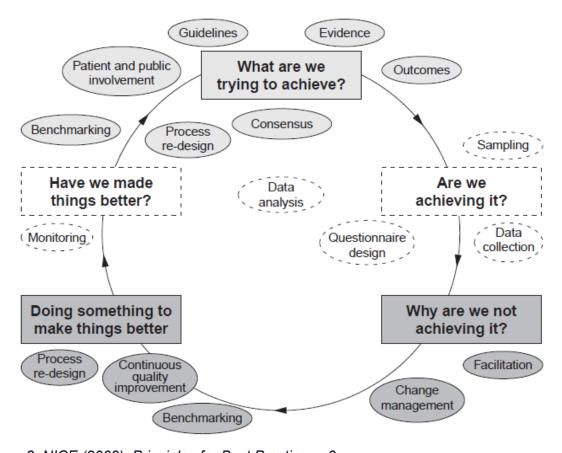


Figure 2: NICE (2002): Principles for Best Practice, p.3

In brief, firstly the focus of the audit is identified. This is usually directed by national and international professional guidelines and policies which set the standards for care given to patients. Where these are not available, services may consider looking to local strategic priorities and targets for care; and/or evidence available from research about what good clinical practice looks like. Services may wish to consider the standards outlined in this

Auditable indicators 54



document to identify a specific focus of your audit in relation to the psychological support for adults living with HIV.

Secondly, the agreed focus of the audit needs to be operationalised into clearly defined, objectively measurable criterion (e.g. "all non-urgent referrals for psychological assessment were offered an assessment within 18 weeks") and an objective standard needs to be set which indicates whether compliance is met or not (e.g. "compliance is defined as 95% of referrals having been offered a psychological assessment within 18 weeks"). Third, a suitable method for data collection must be designed and implemented; and fourth, a suitable action plan based on the results must be decided. For example, if the standards are not being met; the reasons why must be understood and a plan of action to improve compliance must be undertaken. In the instance that services are compliant with standards, it is equally important to understand the factors contributing to success so that high standards may be maintained. Re-audit is an optional fifth step to assess for improvement in clinical practice.

Both NICE [293] and the Health Quality Improvement Partnership [294] outline best practice in clinical audit in more detail and should be consulted.

## Audits for psychological support in HIV

Given the diverse nature of service provision nationally, it is not practical to set specific audit indicators for each standard that has been outlined in this document. Rather services should use these standards in combination with local specifications and drivers to focus audit priorities. However, below are some suggested 'super' and 'within service' indicators that services may wish to consider. These complement the five auditable indicators already suggested by the BHIVA *Standards of Care for People Living with HIV* [164].

Below are suggested 'super' indicators for providing high quality HIV psychological support nationally:

1.	Does the service have a clinical lead for psychological support?	Y/N
2.	Does the service have set pathways for the following:  a. Psychological screen  b. Assessment  c. Intervention	Y/N
3.	Is competent psychological support available either within service or via an external service?	Y/N
4.	Are people living with HIV consulted in the planning of psychological provision?	Y/N

These standards are met if services can answer "yes" to each point.

Auditable indicators 55



Below are three suggested 'within service' indicators to ensure psychological care is embedded at all relevant timepoints:

1.	Proportion of people living with HIV offered the opportunity to discuss psychological well-being in every clinical appointment.	95%
2.	People living with HIV are offered timely, compassionate, culturally competent support at time of diagnosis <i>or</i> on transfer into the service.	100%
3.	Where distress has been identified, people living with HIV have been referred for psychological assessment.	95%

## **Data gathering methods**

The above questions can be answered by:

- Retrospective case note review
- Service user surveys
- Staff and/or service management surveys.

Auditable indicators 56



## **Good practice examples**

All case studies use pseudonyms and are an amalgamation of anonymised clinical examples.

### Example A: Holistic health strategies for long-term health

A holistic approach integrates lifestyle practices, psychological resilience and accessible healthcare to manage the physical and mental wellbeing of people living with HIV over time.

#### Example B: Enhancing HIV care through embedded peer support in NHS clinics

Embedding peer support in NHS HIV clinics improves care by providing social support, addressing stigma and fostering collaboration between peer navigators and clinical teams.

#### **Example C: Community-driven co-production in HIV support services**

A co-production model in HIV support services involves people living with HIV in planning and decision-making, enhancing service delivery through collaboration with a psychology team.

### **Example D: Utilising clinical conversations for psychological assessment**

An empathetic approach in routine consultations uncovers psychological issues, leading to valuable support and targeted interventions.

## **Example E: Comprehensive HIV care through integrated psychology services**

An in-house psychology team enhances HIV care through diverse therapies, multidisciplinary collaboration and tailored support for mental health management.

#### Example F: Collaborative HIV support services driven by community feedback

Adapting HIV support services based on community feedback improves engagement, reduces isolation and fosters involvement through tailored group sessions and online programmes.

#### **Example G: Integrated pathway for cognitive symptom management**

An in-house psychology service uses structured screening, assessments and management plans to address cognitive symptoms in a large, aging HIV population.

## Example H: Impact of in-house HIV psychology on engagement and adherence

In-house specialist HIV psychology helps individuals address trauma-related non-adherence, re-engage with healthcare and improve health outcomes.



### Example I: Leveraging in-house HIV psychology for sustained support

In-house specialist HIV psychology supports individuals to regain stability, maintain adherence and find renewed purpose through therapeutic relationships and swift assessments.

### Example J: Proactive and trauma-informed care through in-house HIV psychology

In-house HIV psychology and a trauma-informed approach enable consistent support, treatment and care planning for individuals with severe adherence challenges.

## Example K: Integrating generic psychological therapies into HIV care

Integrating NHS psychological therapies into a small HIV service provides culturally competent support and fosters collaboration between HIV and mental health teams.

## **Example L: Complex care model for HIV services without in-house psychology**

A specialist nursing team without in-house psychology support creates a complex care model using collaborative plans, dual relationship building and community integration.

## Example M: Embedding psychological support in the HIV diagnosis process

Embedding psychological support in the HIV diagnosis process helps manage distress through immediate emotional care, follow-up and access to in-house and community resources.

#### Example N: Expanding access to psychological support in Northern Ireland

A coordinated network improves access to psychological support for people living with HIV through trauma-informed care, direct referrals, remote clinics and strong partnerships.



## **Example A: Holistic health strategies for long-term health**

The example describes the self-care measures a person living with HIV since the 1990s takes as part of a holistic approach to health. It shows how covers lifestyle practices and access to convention healthcare combine to benefit physical and mental wellbeing over the life course.

I've been living with HIV since the 90's, before ART, so have been learning how to self-manage both my mental and physical health over a long time period. For a few years after getting diagnosed, I had low self-esteem and had some bad experiences which meant my mind and body were in a pretty poor state. Over the years, I've accessed a wide range of psychological support (NHS, charity, private therapy and work-based EAP scheme), have educated myself and rebuilt my social life. This means I'm now at the point where self-management with occasional additional support is enough.

For me, there isn't really a separation between physical, emotional and psychological health, they are interconnected. This means I have to manage myself in a holistic way and take a preventative approach. Most of the things I do on a day-to-day basis to stay well are normal 'healthy living' tips. I also read a lot about health and wellbeing and try to make changes in my life to integrate this knowledge. I know how to get access to psychologists through my HIV clinic or GP, but I try to stop myself from getting to crisis point by making sure my diet has all the nutrients I need, exercising regularly, drinking lots of water, getting good sleep and meditating. I don't smoke and only drink alcohol infrequently. I really notice a different in my mood when I am doing these things, especially exercise which increases my resilient and ability to deal with stress.

I have been going to the same city-based HIV clinic for my care for 20 years and know the doctors and nurses very well. They have excellent wrap round support that is essential to keeping my mental health stable. If I have any concerns about medication I phone the pharmacy; worries about symptoms, I ring the HIV nurses or go for a walk-in appointment with the doctor. Having fast access and dealing with things quickly helps me stay balanced and not go into full-stress mode. When something happens (as it regularly does) to do with HIV stigma or other incidents that feel like injustice I can get very distressed and it knocks me off kilter, so at times like this I usually call one of the HIV charities. A few years ago, I started feeling depressed for no apparent reason and tried anti-depressants, but these didn't really work for me. Then I my GP prescribed me HRT and I found this really made a difference, so I think the issue might have been hormonal. I can't assume everything is HIV-related!

Starting full-time work has been excellent for my self-esteem, but a few years back I experienced some discrimination which made me feel very anxious. Luckily, I found out about Access to Work and got a grant for a work coach. I've reapplied for this and had a coach for a few years now. It really helps with the pressure that comes with working whilst managing a long-term condition, especially because now I choose not to share my status at work. As I get older, I'm getting more conscious of brain health and I can feel my system reacting differently to things, like I'm more sensitive. For example, I feel down if I drink alcohol or don't get enough sleep and I get anxious and burnt out if I push myself too hard.



So, I am taking my health more seriously and trying to prioritise keeping myself well and stable. Recently, the best things I've found to help with my mental health are my spiritual practice and good old-fashioned friendship.



## Example B: Enhancing HIV care through embedded peer support in NHS clinics

This example illustrates how embedding peer support within NHS HIV clinical services enhances comprehensive care by providing essential social support and addressing stigma, while fostering integration and collaboration between peer navigators and clinical teams.

A service in the south of England has developed an excellent practice where people living with HIV actively deliver support into the clinics. People living with HIV run a key social care service, providing social support such as housing, destitution support, benefits and immigration advice. The staff are highly knowledgeable about support systems and provide essential information alongside actively challenging stigma and shame.

Peer navigators employed by an HIV community service work within the clinic and are supervised by the HIV social care coordinator who is employed by the NHS trust. The trust pays the HIV community service to deliver the support in clinic on a daily basis. The team is intrinsically linked with the medical and psychology teams and attends team meetings, MDTs and training/CPD sessions where possible. A weekly psychosocial supervision meeting allows the social care team, psychology team and clinical nurse specialists to learn from one another and work in an integrated and supportive way. This service has received outstanding feedback from people using the service, staff and the global HIV community.



## **Example C: Community-driven co-production in HIV support services**

This example describes a collaboration between a community support service and a specialist HIV psychology team to deliver comprehensive, innovative services involving people living with HIV in every aspect of support and decision-making.

An HIV community support service based in northeast England connects and supports people living with HIV and have operated for 30 years. It has excellent networks within the HIV sector and beyond. They currently support 150 people living with HIV, with the input of 20 volunteers living with HIV. The service offers a wide range of support and many of the projects have co-production at their core. Strong relationships have been fostered with a local HIV clinic which has a well-resourced specialist HIV psychology team. They have worked alongside each other for decades, collaborating to provide innovative services that meet the needs of the local population. Support services include:

- Peer support and peer mentoring, one-to-one support for those newly diagnosed and those with complex needs and offer a range of courses and sessions that promote connection and support people to live well with HIV (Level 1 and 2).
- Hosting of the 'Start Making Sense' course, a five-week psychology-led psychoeducation group for those who have been affected by trauma (Level 3 and 4). The course has been developed with the feedback of attendees living with HIV, who helped in the design of a logo and handbook to support the group and attendees have been instrumental as 'graduates' of the group in encouraging those considering the group by meeting with them and sharing their experiences. They also host psychology cafés aimed at exploring topics like worry, sleep, stigma and healthy relationships with peers (Level 2). Each topic is chosen by the HIV community.
- A newly diagnosed course, to support people to come to terms with an HIV diagnosis. The course is co-facilitated by people living with HIV and benefits from the stories of 2 people from the HIV community and support from the MDT from the local clinic.
- Community input into a multi-disciplinary team based at the local hospital addressing the issue of retention in care, providing a crucial link to the views and ideas of the HIV community. For example, there has been consultation on ideas for engagement with those out of care, wording for letters and texts and have proposed a name change for the department.
- Members are actively involved in many aspects of the community service. They speak at newly diagnosed courses, co-facilitate HIV training, share their stories at workforce training for healthcare professionals, develop and deliver projects and are representatives on strategic regional steering group meetings, ensuring the HIV community have a robust voice, influence and involvement in service improvements and service delivery and implementation of the HIV Action Plan.
- Provision of community support to the HIV psychosocial multi-disciplinary team at a local clinic by attending their weekly meeting, enabling proactive work to support



those with challenges at engaging consistently and offering targeted peer support to those who need it most.

- Member representatives meet with the trustee board and senior leadership team of the community service regularly, to help guide strategic decision making.
- The psychology team offer training sessions, reflective practice and supervision to the community staff, which increases their skills and efficacy at supporting a large cohort of people with complex needs living with HIV locally.



## **Example D: Utilising clinical conversations for psychological assessment**

This example demonstrates how an attentive and empathetic approach during routine clinical consultations can uncover deeper psychological issues, leading to valuable support and intervention.

Makalo attended his regular six-monthly medical clinic and the consultation began with an open, general question "How have you been lately?" To which Makalo said "Fine, feeling okay". The consultation continued, with all results checked and the feedback that medically, all was well.

At the end of the appointment, the consultant said, "Is there anything else I can do for you today?" which resulted in another opportunity for checking in with the Makalo's general wellbeing. Makalo responded to this (half-jokingly) by saying "Only if you can find me a man!" as he was walking out of the door. This could have been passed off as just humour, however, due to the strength of their interpersonal relationship developed over many years, the consultant was able to draw on his understanding of Makalo to recognise that this 'joke' also communicated something more serious.

At this point the consultant invited the patient to sit back down and asked, "Is there anything else that you're wishing to communicate here, because it sounds like you feel quite sad about this... do you feel a little alone?" Makalo was then able to open up about feeling quite isolated and lonely and wanting to connect more but not being sure how to do this.

Makalo later reflected that the consultant taking his 'quip' seriously and drawing upon their established clinical relationship to 'read between the lines' rather than just leaving it as a 'joke' really helped him. He noted that he has struggled to communicate feelings in the past and can find it difficult to get in touch with emotions. The ability of the consultant to recognise and read the cue and show compassionate concern, allowed him to feel that the issue was not going to be dismissed, diminished or seen as something unimportant. Makalo expressed that it was helpful that the consultant gently teased this information out, supporting him to name what he was feeling so that he could seek support. It was at this point that the consultant talked to the patient about a referral to in-house psychology to explore relational issues and barriers to intimate contact. Makalo was pleased that a referral could be made to support him with this concern.



# **Example E: Comprehensive HIV care through integrated** psychology services

This example reveals how a dedicated in-house HIV psychology team can enhance care by providing diverse therapeutic interventions, multidisciplinary collaboration and tailored support for various patient needs, to ensure holistic management of HIV.

In a service with about 3,105 people living with HIV, the psychology team receives 200–250 referrals annually. The team includes a lead clinical psychologist, two clinical psychologists, a counselling psychologist, a cognitive behavioural therapist and a trainee. They work closely with consultants, doctors, nurses, psychiatrists, pharmacists and research nurses within the multidisciplinary team. Outpatient referrals to the psychology team receive assessments and interventions to address treatment adherence and HIV-related coping difficulties.

Individual therapy, following national guidelines (BHIVA/BPS/BASHH/NICE), consists of 12 sessions of 50 minutes each, available in-person, by video, or telephone and utilises evidence-based approaches such as cognitive behaviour therapy, Acceptance and Commitment Therapy (ACT) and narrative therapy. The team also provides services to inpatients, antenatal patients and harder-to-reach populations. For inpatients, they attend weekly HIV MDT meetings to discuss complex cases involving adherence, medical management and social factors, offering assessments and follow-ups throughout and after hospital stays.

The antenatal services involve monthly MDT meetings to support women with HIV throughout pregnancy, addressing HIV adjustment, mental health issues, sharing status, and testing for children and partners. Weekly MDT meetings focus on harder-to-reach women with complex psychological needs. The psychology team offers neuropsychological screening for cognitive issues and psychological support for individuals' partners and families, prioritising new diagnoses and ward patients. Psychologists lead bi-monthly complex case meetings with various healthcare professionals to discuss challenging psychosocial cases and provide teaching on psychological theories and skills. They also offer group sessions, collaborate with HIV charities and deliver virtual webinars and inperson mental health training with international reach.

The psychologists offer a supervision space for other members of the team including nurses, hypnotherapist and upcoming peer worker, in addition to supervising other psychologists. Services are being extended to offer routine drop-in reflective space for MDT members. Participating in audit and service reviews is key to offering a high-quality service and establishing different pathways. The psychology service conducts annual audits to monitor outcome of all referrals. Questionnaires are implemented to capture patient feedback and experiences of using the service. The PHQ-9 and GAD-7 are routinely used to capture effectiveness of therapy and going forward, the PREMs outcome measure will be added. Regarding the wider dissemination of work, the service has presented and had multiple abstracts accepted at BHIVA and EACS.



# Example F: Collaborative HIV support services driven by community feedback

This example demonstrates how a multidisciplinary team in the East of England effectively adapted HIV support services based on community feedback, offering tailored group sessions and online programmes to enhance engagement and reduce isolation despite challenges.

The BHIVA Psychological Standards recommend that people living with HIV receive comprehensive information, access peer support, participate in service planning and evaluation and receive care from trained professionals. A small multidisciplinary team in HIV clinics in the East of England has addressed these recommendations over the past 11 years by offering group support and information, shaped by feedback from service users and adapted to available resources and local needs. A 2013 survey found that about 50% of clinic users were interested in attending groups, with topics like 'medication', 'life after diagnosis', 'work/life balance', and 'health management' being most popular. Other topics of interest included 'travel', 'stress and mood management', 'relationships', 'the law', and 'sharing status'. Those not interested felt they already had enough information or were deterred by travel, time constraints, language barriers, or concerns about disclosing their HIV status.

Commissioning changes caused a shift from acute to community trusts, pausing the implementation of group work. In 2016, during a more stable period, the agenda was revisited. Between 2016 and 2020, the team launched five different face-to-face groups across three clinics through small quality improvement projects. With no dedicated funding and limited clinical time, the team adopted an opportunistic approach, utilising trainees, short-term development funding and professional interest. Each group was tailored to attendees' needs, from structured psychoeducational sessions with specific topics to informal peer-support groups. All involved multidisciplinary collaboration, with a clinical psychologist leading and a pharmacist providing medication content. Doctors, nurses and health advisers also contributed and third-sector providers participated when available. The COVID-19 pandemic interrupted the programme in 2020, but it resumed in 2023 with an online group trial, offering six structured, psychoeducational sessions on 'Living well with HIV', led by subject matter experts within the multidisciplinary team.

Key learnings from this process indicate that, although group attendance was small, participants gave very positive feedback and valued the opportunity to engage with the resource. However, stigma, fear of disclosing HIV status and practical barriers limited access, with those who attended often encouraged by a trusted practitioner. Structured groups with specific content were particularly effective for recently diagnosed individuals or those ambivalent about attending, while online groups offered greater confidentiality, though many participants preferred in-person meetings. Measuring outcomes was challenging, but direct participant feedback proved most valuable, highlighting benefits like receiving quality information, having a safe, non-judgmental space, feeling supported and reducing isolation through shared experiences. Group involvement also boosted participants' confidence, leading to further engagement in activities like 'expert by experience' training, co-producing research, or providing informal peer support. The experience underscored the need to seize



opportunities for new projects despite inevitable service changes and the importance of dedicating specific resources to ensure their success. Participants expressed a strong desire for these opportunities to continue and be accessible to others.



# **Example G: Integrated pathway for cognitive symptom** management

This example highlights the benefits of an in-house psychology provision within an HIV service in the South of England, where a multidisciplinary team utilises a structured pathway for annual cognitive screening, comprehensive assessments and individualised management plans.

An HIV service in the south of England with a comparatively large and ageing HIV population have developed a pathway for the screening and management of cognitive symptoms. All people attending the HIV service are asked the European Clinical Society (EACS) screening questions annually by nurses conducting the standard of care annual health check. Individuals that have cognitive symptoms identified by the EACS questions are offered a Montreal Cognitive Assessment (MoCA), which is brief to administer, examines multiple cognitive domains and is sensitive to mild cognitive impairment in general populations. Those who score below a standardised cut-off (26 out of 30) are offered an appointment in the combined HIV and memory clinic embedded within the HIV service.

This service consists of (i) an HIV consultant physician, (ii) a consultant psychiatrist specialising in older adults (iii) a neuropsychologist with a psychology assistant, (iv) a clinical psychologist, (v) a HIV clinical nurse consultant and (vi) virtual support from neurology and neuroimaging services. The clinic operates for assessments for two sessions monthly with an additional monthly follow-up session. In one day, the clinic aims to have completed multiple assessments and to triangulate the information from these with history and investigations to generate for each referral a full assessment and management plan.

Prior to clinic attendance, multidisciplinary virtual case-based discussions (without patients present) are organised, including a background review, evaluation of current knowledge/ assessments and a review of the need to request further investigations (e.g. MRI or Lumbar Puncture (LP)) prior to assessment. The person living with HIV is interviewed jointly by the consultants, psychiatry and clinical psychology. Relatives or friends are encouraged to attend the clinic assessment, to provide a collateral history if relevant/appropriate. A detailed neuropsychological assessment is completed which compares pre-morbid function estimates to current performance across multiple cognitive domains, including memory, attention, language processing, visuospatial processing and executive functioning. All results are discussed by the multidisciplinary team and the person living with HIV, following which a formulation and management plan is agreed, co-produced by all.

A variety of interventions, referrals and advice are then offered. These include a management of mental health issues, review, switch or intensification of current ART, review of co-medications, cognitive remediation therapies, optimisation of the management of comorbidities including cardiovascular health, management of sleep disorders and social prescribing interventions such as exercise and peer support. Follow-up appointments and reassessments are offered as required and care plans updated and amended as necessary.



## Example H: Impact of in-house HIV psychology on engagement and adherence

This case study illustrates the benefits of in-house specialist HIV psychology by showing how a collaborative, psychologically informed approach helped a young woman with vertically transmitted HIV understand trauma and re-engage with healthcare services.

Tee is a 25-year-old Black British women who has vertically transmitted HIV. She has a five-year-old child and was previously under the care of the paediatric part of the HIV service and has now transitioned to the adult service. Both teams experienced considerable issues supporting Tee to take antiretroviral treatment (ART). As a result, she had a high viral load and extremely low CD4 count, and the team felt extremely worried about her health and wellbeing. Tee had historically declined all offers of referrals for psychological support.

When Tee transitioned to the adult clinic, the MDT began to engage in consultation with psychology. Psychology supported the team to understand psychological aspects of the situation, to think about psychologically informed communication and to manage interpersonal factors. These in-house professional relationships allowed the development of an interdisciplinary approach, which resulted in Tee engaging with the psychology service. Before even reaching the halfway point of the therapy, through a process of psychological formulation, Tee had developed insight into the links between her adherence issues and how she copes with the complex trauma she lives with. She made the decision to begin taking her ART.

Unmet needs relating to childhood experiences were identified and together the psychologist and the team were able to think about how this affected engagement with healthcare relationships. An understanding around the need for proactive and consistent care was developed and a collaborative care plan was made with Tee. Specialist nurses visited at regular pre-agreed times and these visits were spaced further apart as Tee gained confidence in taking her treatment independently. She attributed the improvement in her adherence to this support, as well as understanding the trauma that had been triggered by taking tablets.

Unfortunately, Tee then experienced a serious health scare. As a result, she returned to historical coping styles (which is common in times of high distress), such as withdrawing from support (including healthcare relationships) and feeling unable to take her ART. However, having the flexibility and responsiveness of in-house psychology, Tee could access space to make sense of her experience and was supported to re-engage. On revisiting the psychological formulation, Tee was able to understand her response and opted to focus on recommencing her ART. This contrasts with previous patterns of withdrawal, where she would avoid any discussion of her adherence. Additionally, with Tee's consent, the psychological understanding was shared with the team, meaning there is a now a shared language between Tee and her medical healthcare professionals. This has beneficial implications for ongoing care delivery, even when psychology is not directly involved.



# Example I: Leveraging in-house HIV psychology for sustained support

This case study demonstrates the benefits of in-house specialist HIV psychology by showcasing how a pre-existing therapeutic relationship and a swift psychological assessment helped a man to regain stability, maintain treatment adherence and find renewed life purpose.

Barry is a Portuguese gay man in his 50's and he was recently re-referred to the specialist HIV psychology service, having received therapy before. During the last care episode, Barry had been suicidal and the psychological assessment had resulted in him being linked in with community mental health services. He was not taking his ART and his health was beginning to deteriorate. Psychological therapy worked alongside the community support to help Barry explore the trauma that underpinned his adherence problems and consequently he was able to re-commence treatment. Unhelpful coping strategies were identified and, with support, Barry was able to implement alternative ways of coping. The therapy also helped him identify his values and skills and resulted in him returning to work in a role that utilised his strengths and therefore increased his confidence and self-esteem.

Barry was re-referred due to a considerable deterioration in his mood after some stressful life events. Additionally, COVID had led to his work role ending and the community mental health team had withdrawn their support based on a decision that it was no longer required. An initial assessment was offered to explore Barry's distress and needs. He reported that he had been struggling again, using some old coping strategies and was having thoughts about coming off treatment. The benefit of having previous contact (existing knowledge and relationship) was that we were quickly able to revisit the psychological formulation of his historical difficulties and draw on his previous ability to make positive change. The problem of withdrawal and isolation was quickly identified as central and again the exploration of value-based goals resulted in a plan of action for Barry, which instilled a sense of purpose and hope. Specialists came to a mutual conclusion that another therapy process was not required and he felt empowered to move forward managing his issues independently. He was referred to a relevant community-based service, as agreed with Barry, where he could pursue a role that was fitting with his skills and experience and would also re-connect him socially. He did not come off his ART.



# Example J: Proactive and trauma-informed care through in-house HIV psychology

This case study illustrates the benefits of collaborative working between in-house specialist HIV psychology and multidisciplinary team to provide consistent support, address psychological barriers to treatment and develop a proactive care plan that better meets complex needs.

Carol is a White British female in her 40's who has complex trauma-related psychological issues and social problems. Due to high levels of distress related to her HIV diagnosis, she has had a long history of adherence difficulties. This has resulted in her becoming extremely unwell repeatedly, with many inpatient admissions to hospital. Although the MDT (nursing, doctors and psychology) have always worked hard to support Carol, this has often been in a reactive way as 'firefighting' is often required in response to frequent crises. This has been due to the complicated social situation that often brings elevated vulnerability in many ways.

Over the COVID lockdown, the MDT did not have a lot of contact with Carol, as she could not come into hospital. Telephone or virtual appointments (medical, nursing or psychology) were not possible due to shared home environment that was not a safe space for her. When she was finally able to come back in for a face-to-face appointment with psychology, it was clear that her health had severely declined and there were issues around ingesting nutrition and medication. Carol was now wishing to take ART. Having an in-house psychologist meant that it was easy to utilise existing relationships with the MDT to share historical knowledge, discuss Carol's healthcare and make a plan of action. A planned admission was proposed to address the gastroenterological problems to allow treatment absorption. Although Carol was initially very reluctant (having previously had negative experiences in hospital) psychology were able to work with her through the potential drawbacks and benefits of this plan and she eventually opted to for an admission.

The inpatient admission was very difficult for Carol, as her distress was high and there were concerns about her capacity to make decisions at times. However, the team were able to work together the get a biopsychosocial understanding of the issues and try to make care plans that best met Carol's needs. There were significant concerns for Carol's life at one point and unfortunately she was declining assessments and treatments offered, due to her escalating distress. Due to having in-house psychology, input was flexible and regular, meaning that psychological obstacles to treatment could be addressed. Psychology and the specialist nursing team worked closely together, meeting frequently and sharing information to ensure a consistent approach to care (essential when there is a history of trauma). As her health challenges escalated to a severe level, the MDT arranged a meeting with Carol to work alongside her to explore her options. With the support of the whole team, Carol was able to choose the option with the best potential outcome for her. Although her psychological and emotional state often fluctuated, which could mean a shift in her thinking, with in-house support, she could work through doubts and make informed choices. As a result of this challenging admission, based on psychological principles/theory, the team created a more trauma-informed care plan. This was a proactive approach, offering a structured plan of consistent care to monitor Carol, rather than responding when she reaches crisis.



# Example K: Integrating generic psychological therapies into HIV care

This example showcases the innovative integration of NHS psychological therapies into a small HIV service in the West Midlands, enabling culturally competent mental health support within familiar clinical settings, improving access and fostering knowledge-sharing between specialist teams.

Please note – this initiative was developed when general therapy services in England were known as Improving Access to Psychological Therapies (IAPT) and so will be referred to this throughout. This service is now called NHS talking therapies for anxiety and depression.

A small HIV service in the West Midlands did not have any in-house psychological/mental health practitioners and so the only option was to refer to generic mental health services via GP surgeries. As the National AIDS Trust (NAT) report [16] had highlighted that these services are not always able to meet the needs of people living with HIV, the service began to consider ways in which people living with HIV could access more culturally competent support for their mental health needs.

The HIV team held some initial meetings to identify the needs of their patient cohort. Once this was clarified, they held discussions with many sexual health service managers, who were linked to shared premises. It felt important to bring IAPT in-house, so that face-to-face appointments in a familiar space could be offered to enable the person living with HIV to feel at ease.

Contact was then made and initial conversations held with an IAPT manager to see if partnership working to offer mental health services for the HIV team would be possible. Identified leaders from the HIV team then met with the counselling team to build up good working relationships and the counselling team came across to the site to meet MDT staff and to become familiar with how the clinics ran.

A pilot study was initiated at one of the smaller clinics, where there was capacity to deliver this service (200-patient cohort). A once monthly clinic commenced, which offered face-to-face sessions alongside the HIV clinic. Individuals also had the option of virtual and telephone consultations. All referrals were emailed to IAPT with a summary of the issues identified and the people living with HIV were booked into the clinics accordingly.

Regular debriefs were held with IAPT to monitor feedback make any improvements and changes, in keeping with needs identified. The consultant offered further educational sessions for the IAPT service to improve their understanding of HIV. The IAPT team reported considerable improvement in their HIV-related knowledge and the associated psychological issues, through working collaboratively. This was beneficial both for people living with HIV who were accessing psychological support and for IAPT staff and their service.

Due to the success of this model, weekly fixed sessions have now replaced the initial monthly ones. There are also plans to roll the model out into three other clinics. This initiative was supported greatly by long-term conditions being on the agenda for IAPT.



# Example L: Complex care model for HIV services without in-house psychology

This example demonstrates how a specialist nursing team developed a care model to integrate community services, supporting people with complex needs through structured plans, relationship building and proactive monitoring, despite lacking inhouse psychological practitioners.

In an HIV service without in-house psychological practitioners, the specialist nursing team developed a support system for people with complex needs, aligning with Level 4 of the matched model. This framework, based on HIV evidence and clinical experience, identifies complex needs as including psychological distress, mental health issues, substance or alcohol use, chemsex with negative impacts, social issues (such as immigration, housing, or domestic violence), adherence problems, complex health comorbidities, need for additional clinical contacts, engagement barriers, frequent DNAs and cognitive problems. Complex needs are identified through clinical contact, either by the specialist nursing team or by the wider MDT who can refer into the complex needs model. Although effort is made for the person who identifies the need to follow-up, this is not always possible. After initial follow-up, a two-practitioner approach is adopted to enable dual relationship building, which aims to avoid circumstances where absence of a practitioner leaves the person unsupported.

A collaborative care plan is agreed with the person living with HIV, as this allows the person to be directly involved and have agency in their care. An agreement is made regarding the form (e.g. text or telephone call) and frequencies of proactive 'check ins', which aim to create a support net for the person and allows the practitioners to monitor psychological needs and any safeguarding issues. Support can be intensified or scaled down dependent on the person's situational context and stress levels. The list is reviewed monthly and people can be stepped off the list if sufficiently supported in the community and or able to self-manage.

The care plans also include linking the person in with relevant community support services, including peer support and other NHS care agencies. The team have developed a resource folder, which includes helpful communication prompts and aids, services to signpost to and guidance around safety planning. A RAG (red, amber, green) rating system is used to assess needs and risk. This links to clear guidance about what constitutes red, amber or green, which is embedded in the NHS trust policy and procedures and relates to local mental health service pathways.

In terms of development and support of the nursing team running the model, a training needs analysis is being developed, which documents staff training requirements in terms of psychological support and opportunities for further development. The use of simulated practice (role-playing complicated conversations) also helps build skills and confidence. There are also links with a professional nurse advocate, who offers support, supervision and exploration of development needs. Access to reflective practice to support processing of emotional aspects of the work has also been negotiated with another local HIV service (same trust) that does have in-house psychology provision.



# **Example M: Embedding psychological support in the HIV diagnosis process**

This case study illustrates the integration of psychological support in the new diagnosis process, where a specialist nurse provided immediate emotional support, coordinated follow-up care and facilitated access to in-house psychology and community resources.

Patricia is a woman in her 30's who received an HIV diagnosis in a specialist nurse-led clinic. The diagnosis came as a major shock, triggering overwhelming distress. She expressed deep concern about telling her family and felt she lacked the capacity to do this alone. Following the clinic's ethos, the specialist nurse, experienced in supporting people with complex psychological issues, offered immediate emotional support. Alongside providing up-to-date HIV information to ease health-related fears, the nurse ensured Patricia understood issues of safety and confidentiality. Given Patricia's complex trauma history, additional avenues for both immediate and longer-term psychological support were explored.

The nurse was particularly concerned as the weekend approached and Patricia would not be able to access specialist support. A next-day nursing follow-up was arranged (on Friday) and Patricia was signposted to urgent mental health resources, including crisis phonelines, Samaritans and the option to go to A&E by ambulance if she felt unable to keep herself safe. Access to peer support from the local HIV community service was encouraged and a possible referral to the in-house specialist HIV psychology service was discussed. During the follow-up call the next day, the nurse checked in on Patricia's understanding of the HIV information she was given and (re)provided any information required. Patricia was also made aware that she could contact the on-call registrar of the HIV service over the weekend if she needed any advice about her condition or health-related worries. Again, emotional support (e.g. listening, empathy, normalisation and validation) was provided, pathways to support revisited and plan for the nurse to call her on Monday was put in place.

During the telephone call on Monday, Patricia revisited her fears about sharing her diagnosis and support was offered. The news was not received well, so the nurse again provided psychological support to manage Patricia's distress. The nurse then contacted the in-house HIV psychologist to discuss Patricia's complex needs and develop a psychologically informed care plan. With Patricia's consent, a referral was made, allowing the psychologist to gain insight from the nurse on the best approach to support engagement. It was conveyed that a face-to-face assessment would be most comfortable for Patricia and the nurse facilitated her attendance.

As part of a proactive nursing support plan, the nurse offered weekly telephone calls to provide psychological support during the initial adjustment period. A referral was also made to the community service for peer support. Although Patricia was initially hesitant about attending, the nurse's liaison with the community team helped arrange a sensitive, phased approach that made Patricia feel safe to engage. As she began to participate, nursing support was gradually reduced, first to fortnightly, then monthly and finally to a point where Patricia knew she could contact the nurse if needed. This collaborative support from specialist nursing and the community helped hold Patricia's distress, enabling her to adjust



and, by the time she reached the top of the psychology waiting list, to have a more stable base from which to engage in trauma-focused therapy.



# Example N: Expanding access to psychological support in Northern Ireland

This example demonstrates how a network of statutory and non-statutory services in Northern Ireland improves access to psychological support by integrating trauma-informed care, direct referrals, remote clinics and partnerships with health, social care and community organisations.

Psychological support for people living with HIV in Northern Ireland is delivered and coordinated through a stepped framework with clear pathways between various statutory and non-statutory services. All practitioners involved in HIV care use a trauma-informed approach, supported by training and education from a full-time in-house practitioner psychologist with specialist knowledge in HIV.

Practitioners can refer people living with HIV for psychological support to various members of the multidisciplinary HIV team, based on assessed needs. This support may include brief intervention and counselling with the health advisor team, social support from HIV specialist social workers, or specialist psychological intervention from the in-house HIV psychology service. A self-referral mechanism is also available for brief psychological support with the health advisor team, who can then refer to the appropriate level, if required.

Direct pathways have been established between the HIV psychology service and HIV treatment centres in other Health and Social Care Trusts across Northern Ireland, where remote clinics are offered to enhance access to psychological support.

Outside the HIV clinical care team, a direct pathway with the hospital mental health liaison team allows people living with HIV to be referred for outpatient mental health assessments. This team provides one clinical session per month at the HIV clinic, a pathway established following an audit of complex mental health needs and their impact on engagement with care. The mental health liaison service offers assessment only and connects the service user with the appropriate community mental health team for follow-up if needed.

Bi-monthly referral and case discussion meetings between the HIV psychology service and the mental health liaison team facilitate appropriate intervention and co-working. In response to local needs, direct referral pathways have also been developed with the community addictions team, substitute prescribing team and inclusion health services (healthcare for people experiencing homelessness). These pathways have clear suitability criteria that must be outlined by the HIV practitioner as part of the referral, allowing direct access to additional support without involving a GP.

Partnerships extend to external agencies, including local charities for people living with HIV, with well-coordinated pathways at all levels based on strong relationships. All practitioners offering psychological support provide outreach services, where support sessions can be delivered off-site in collaboration with other services or external agencies. Building good relationships and partnerships across services and agencies remains a priority, supported by shared training, education and resources.



### **Appendices**

### **Appendix A: Glossary**

Term	Definition
Assessment	<ol> <li>Evaluation of a person using selected skills such as history-taking, physical examination, laboratory, imaging and social evaluation to achieve a specific goal.</li> <li>Appraisal or analysis of conditions, disorders, data, or a person's overall state.</li> </ol>
Clinical psychology	Aims to reduce psychological distress and promote wellbeing through systematic application of knowledge derived from psychological theory and research.
Cognitive	Pertaining to cognition, i.e. the mental activities associated with thinking, learning and memory.
Cognitive assessment	The process of systematically gathering test scores and related data in order to make judgments about an individual's ability to perform various mental activities involved in the processing, acquisition, retention, conceptualisation and organisation of sensory, perceptual, verbal, spatial and psychomotor information.
Cognitive difficulties	People who have cognitive difficulties may have short or long- term memory problems and experience challenges in starting tasks, making decisions, planning and organising.
Cognitive functioning	Any mental process that involves symbolic operations, such as perception, memory, creation of imagery and thinking. It encompasses awareness and capacity for judgement, problem solving and decision-making.
Cognitive impairment	Mental disorders distinguished by a limitation of mental functions, such as memory, comprehension and judgement. Impairments can range from subtle difficulties, like trouble remembering appointments, to severe impairments that require high levels of support.
Cognitive rehabilitation	Describes the non-medical treatment of cognitive impairment, often involving services provided by occupational therapists, clinical psychologists, neuropsychologists and speech and language therapists.
Cognitive screening	The first step in detecting dementia and other neuropsychiatric syndromes, involving initial cognitive assessments to determine whether further investigation is necessary.



Term	Definition
Cognitive Behavioural Therapy	A psychotherapeutic approach that aims to address dysfunctional emotions, behaviours and thoughts through structured, goal-oriented therapy.
Counselling psychology	A branch of applied psychology focused on addressing emotional, social and psychological issues to promote wellbeing and functioning.
Counselling and psychotherapy	Umbrella terms covering a range of talking therapies that help clients resolve emotional, psychological and relationship issues in a context of confidentiality and clear ethical boundaries.
Dementia	An acquired loss of cognitive function that may affect language, attention, memory, personality and abstract reasoning.
Formulation of psychological problems	Developing a coherent description of a person's psychological difficulties, using all relevant information about the person and their context, based on psychological theory.
General rehabilitation	Restoration, following disease, illness, or injury, of the ability to function in a normal or near-normal manner.
Health psychology	A branch of psychology that applies psychological research and methods to the promotion and maintenance of health, the prevention and management of illness, the identification of psychological factors contributing to physical illness, the improvement of the healthcare system and the formulation of health policy.
Liaison psychiatry	A sub-specialty providing psychiatric treatment to people attending general hospitals, addressing the intersection of physical and psychological health.
Low-intensity support	Emotional/social support services, including mutual support networks, befriending services, home-visiting services, telephone support services and computer-mediated social support, designed primarily to provide companionship and emotional support.
Mental health	Defined by the World Health Organisation as a state of wellbeing in which individuals realise their abilities, can cope with normal stresses, work productively and contribute to their community.
Mental health service	Provide a wide range of support, including psychological therapies, counselling, community-based services and psychiatric care, aimed at improving mental wellbeing and managing mental health conditions
Mental health specialists	Practitioners within NHS mental health system, specifically clinical psychologists, psychiatrists and psychiatric nurses.



Term	Definition
Mental health team	Multidisciplinary teams of mental health specialists within NHS services, which may be based in community or hospital settings.
Neurocognitive	Cognitive functions closely linked to the function of particular areas, neural pathways, or cortical networks in the brain.
Neurocognitive disorder or problem	A reduction or impairment of cognitive function in one of these areas, especially when physical changes in the brain are evident.
Neurocognitive functioning	Refer to cognitive functioning for more details.
Neurorehabilitation	A process that helps individuals who suffer from impairment following neurological diseases regain their former abilities or achieve their optimum capacity.
Peer support	A system of giving and receiving help founded on key principles of respect, shared responsibility and mutual agreement on what is helpful. For this document, it refers to support provided by people living with HIV for others in similar situations.
Practitioner	For the purposes of this document, anyone providing psychological support, including healthcare professionals and peer support workers.
Psychoeducation	A form of education providing information about the likely causes of current psychological difficulties and strategies to deal with them.
Psychological assessment	A structured procedure that gathers information from and/or tests a person to evaluate an emotional, cognitive, or behavioural complaint.
Psychological disorder	A pattern of behavioural or psychological symptoms that impact multiple life areas and/or create distress for the person experiencing these symptoms.
Psychological screening	Asking individuals a set of structured questions to identify whether referral for a more in-depth assessment is needed or signposting to low-intensity support.
Psychological support	Support aimed at helping people enhance their cognitive, emotional and behavioural wellbeing.
Psychological symptoms	A subjective manifestation of a pathological condition. Symptoms are reported by the affected individual rather than observed by the examiner.
Psychological therapy/therapist	An inclusive term covering anyone with therapeutic training in models including psychodynamic, cognitive behavioural, artsbased and systemic approaches.



Term	Definition
Psychiatry/psychiatric	The medical science of diagnosing and treating mental health problems using a range of interventions, most commonly drugs and psychotherapies.
Risk assessment	In psychology refers to the formulation and evaluation of potential psychological or behavioural risks an individual may pose to themselves or others. This includes assessing the likelihood of harm, self-harm, or deteriorating mental health, understanding these issues in context and identifying protective factors to inform patient centred interventions and support strategies.
Quality of life	Overall sense of wellbeing, including physical, mental, emotional and social health and perception of one's position in life in relation to goals, expectations and the broader social and cultural context.
Screening	Assessments or enquiries used to identify individuals at risk of psychological or behavioural conditions, providing guidance on appropriate interventions or next steps.
Self-help	Refers to self-improvement efforts an individual makes without external assistance, often by using books or reference materials.
Self-management	Learning and practising the skills necessary to manage a chronic condition.
Wellbeing	State of existence characterised by balanced mental, cognitive, emotional and behavioural health, supported by factors such as physical health, happiness, education, leisure activities and a sense of social belonging.



### **Appendix B: Abbreviations**

Abbreviation	Definition
AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral Therapy
BASHH	British Association for Sexual Health and HIV
BHIVA	British HIV Association
BPS	British Psychological Society
СВТ	Cognitive Behavioural Therapy
СМНТ	Community Mental Health Team
CPD	Continuing Professional Development
GAD-7	Generalised Anxiety Disorder-7 scale
GIPA	Greater Involvement of People Living with HIV
GRADE	Grading of Recommendations Assessment, Development and Evaluation
HIV	Human Immunodeficiency Virus
IAPT	Improving Access to Psychological Therapies
LGBTQI+	Lesbian, Gay, Bisexual, Transgender, Queer or Questioning and Intersex, with the "+" symbol representing other sexual orientations and gender identities that may not be explicitly included in the acronym, such as asexual, pansexual, non-binary and others
MedFASH	Medical Foundation for AIDS and Sexual Health
MSM	Men who have sex with men
NHIVNA	National HIV Nurses Association
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
PHQ-9	Patient Health Questionnaire-9
PREMs	Patient-Reported Experience Measures
PROMs	Patient-Reported Outcome Measures
PTSD	Post-Traumatic Stress Disorder
RCT	Randomised Control Trial
UNAIDS	Joint United Nations Programme on HIV/AIDS



### **Appendix C: Processes in the development of the standards**

The process for updating the *Psychological support for adults living with HIV* standards (2011), followed the NHIVNA audit in 2015 [213], which assessed how well these standards were being met within HIV specialist services. Key gaps in service provision were identified, along with recommendations for strategies to improve psychological wellbeing for people living with HIV.

In 2022–2023, a stakeholder consultation was led by the chair of the working group, supported by a research fellow (based at The Open University), to inform the development of updated standards. Key professional and third-sector stakeholders (including clinical HIV specialists, clinical psychologists, and representatives from community organisations) were invited to participate. The consultation was conducted primarily through an electronic survey, with findings analysed and summarised in a stakeholder report [178].

Preparatory work was undertaken by the chair, supported by the managing editor, in late 2023 and early 2024. A working party was established, consisting of 20 authors and 15 contributors, representing BHIVA, BPS, NHIVNA, UK-CAB and other professionals involved in HIV care.

Once the scope and terms of reference were confirmed and a shared understanding was established across the working group, sub-groups were convened to plan the approach and determine how to incorporate findings from the NHIVNA audit and the stakeholder consultation. A protocol and scoping review strategy were developed, with all working group members contributing literature and the managing editor conducting searches. Materials were available to all working group members via a secure shared drive.

Between January 2024 and January 2025, the full working group convened nine times. In parallel, writing sub-groups were established for each section of the standards, including the introduction, matched care model, and indicators, with each sub-group comprising three specialists. These sub-groups independently organised and held their own meetings, feeding into the main group at regular points.

The first draft was completed in June 2024 and underwent internal review, with all working party members providing feedback across all sections. Writing sub-groups incorporated this feedback into revised drafts. Additional small groups were established to lead supplementary work, including gathering illustrative quotes from people living with HIV, collating examples of good practice, and developing indicators. This work involved engagement with commissioners, service leads, charities, community groups and HIV specialists.

The second draft was completed in September 2024, and BHIVA circulated the document for a final round of stakeholder consultation. The working group reviewed the feedback, and the draft was presented at the BHIVA Autumn Conference in November 2024 (<u>can be accessed here</u>), where further input was invited. All feedback was analysed and synthesised into action points, which were incorporated into the final version of the document.

The completed document was circulated to all working party members for final sign-off in April 2025.



# Appendix D: Framework for a specialist HIV psychology business case

When making a case for in-house specialist HIV psychology provision, the following factors will be important to consider and can help provide relevant information and evidence for commissioners and service managers.

### The initial question

Are the BHIVA Standards of Psychological Support for Adults Living with HIV 2025 and the BHIVA Standards of Care for People Living with HIV 2018 and any relevant clinical guidelines being met and if not, what are the gaps in care? This can be evidenced by audit utilising the indicators presented in these Standards.

If a service without existing in-house specialist HIV psychology would like to make a case for this, it will be helpful to contact services that already have in-house HIV specialist psychology provision. The <a href="BPS Faculty for HIV and Sexual Health">BPS Faculty for HIV and Sexual Health</a> may be a good starting point to access this information.

When creating a business plan for HIV specialist psychology, it will be helpful to consider the HIV and mental health context. The following areas will be important to include:

- The high prevalence of distress, trauma and mental health needs in the population of people living with HIV [20, 40-42, 51, 171].
- Reference Undetectable=Untransmittable (U=U) and 95-95-95, highlighting that psychological support can address barriers to adherence and therefore support better health outcomes [6, 33, 164, 215, 280].
- The need for HIV cultural competence and trauma/psychologically informed care in relation to optimum health and psychological wellbeing outcomes [36, 66].
- The benefits of in-house HIV specialist psychology embedded in MDT include:
  - HIV cultural competence (building psychological support around HIV-related needs).
  - o A flexible service able to respond in a patient centred manner.
  - Collaborative working and bidirectional learning between HIV clinicians and in-house psychology able to support the delivery of psychologically informed care by the whole team (teaching, training, supervision, reflective practice and joint working).

It will also be important to reference broader HIV and mental health strategies, that support a person-centred and integrated approach to care. The following will be relevant:

- Five Year Forward View for Mental Health (2016)
- NHS Long Term Plan (2019)



- The Missing Link: HIV and Mental Health (2020)
- Mental Health and Wellbeing Delivery Plan for Scotland (2023–2025)
- Mental health and wellbeing strategy for Wales (2025 to 2035)
- NHS England service specification for adults living with HIV (2024)
- HIV Actions plans for <u>England</u>, <u>Northern Ireland</u>, <u>Scotland</u> and <u>Wales</u>.

### Service area specifics

Consider the specific size and needs of the local population that your clinic serves. Outline specifics of socio-cultural factors and demographics and how these may relate to levels of psychological distress. Also, document any limits to specialist service provision for complex needs in the geographical area, e.g., does easy access to community and peer support exist; is there access to psychological services that address Level 4 complexity. Some generic NHS talking therapies for anxiety and depression only have support equivalent to Level 3 and do not provide clinical/counselling psychology or psychotherapy for interpersonal trauma. It is likely that talking therapy and counselling services will not be able to provide neuropsychological assessment or advice.

### Costs-benefits appraisal

The cost of care is increased by between 45% and 75% for individuals with co-morbid physical and mental health problems. When relating this to HIV services, these higher costs are incurred through:

- More frequent inpatient admissions and re-hospitalisation.
- More frequent consultant clinic appointments.
- Increased ad hoc presentation at services (e.g. contacting specialist nurses, additional clinic appointments).
- Disengagement from services and work to re-engage.

Poor health outcomes in HIV are often the result of ART adherence problems, which are underpinned by psychosocial issues. Additionally, high service utilisation can also be associated with psychological distress, even if physical health issues are managed. Psychological interventions to target distress and treatment adherence, have a beneficial impact on health outcomes and can reduce service utilisation, including (recurring) inpatient admissions. It has been consistently demonstrated, across a range of long-terms conditions, that investment in psychological care more than pays for itself in terms of the savings made [159, 160, 281].

## Implications of insufficient in-house psychology provision (reference this document)

1. Failure to meet referral to treatment (RTT) time standards.



- 2. Falling below HIV national care standards.
- 3. Delivery of the matched care model compromised.
- 4. NHS trust will not comply with commissioning requirements for the management of people living with HIV.
- 5. Poor quality of care, due to lack of culturally competent psychological assessments and interventions.
- 6. Unaddressed mental health problems leading to poor physical health outcomes (morbidity and mortality) and increased admission and inpatient costs, as well as more frequent outpatient attendances, time costs of work to engage people in HIV service with ongoing mental health issues.
- 7. Increased risk of death by suicide.
- 8. Increased pressure on specialist HIV medical and nursing staff, already working at full capacity, to respond to and support complex psychological needs. This is outside of competency parameters as defined by the matched care model and a lack of inhouse HIV psychology prevents sufficient support to non-mental health staff. This is not only detrimental to patient care but can also lead to staff burnout if nurses and clinicians are performing roles outside of competence due to underinvestment in HIV psychology.
- 9. Psychologically informed service development will be limited/not possible.
- 10. Neuropsychological/cognitive assessment will not be available.
- 11. Loss of experienced staff due to under resourcing-related working pressures and stress.

### Employing a psychological practitioner as part of the HIV MDT

A psychological practitioner with responsibilities to set up a service and/or act as clinical lead, should be a band 8c, particularly if managing services across a range of sites. Band 8b is the absolute minimum for a clinical lead role and this should only be considered for small services, based on one site with easy access to a band 8c. Band 7 and 8a practitioners should be employed in addition to the clinical lead with roles more focused on the direct clinical work. Please see [159] for more in-depth guidance:

Pre-COVID, the *UK Renal Psychosocial Workforce Report* (2018) calculated the requirement for 1WTE psychological practitioner per 600 renal patient population, based on 25% of these individuals requiring psychologist involvement. The psychological needs of people living with HIV are substantially more complex. A conservative estimate, based on 35% of people living with HIV requiring referral for Level 3 or 4 psychological needs, identifies a requirement for 1WTE psychological practitioner per 430 HIV patient population [41, 42, 206].

### **Clinical supervision**

Clinical supervision is an integral part of a psychological practitioner's role and is mandatory, not optional. When employing a psychological practitioner, supervisory arrangements must



be put into place. As there are different models of employment, arrangements will vary. If a service has no other psychological practitioners with relevant knowledge, skills and expertise available to supervise, then supervisory support may have to be sought outside of the NHS trust, service, or specialty. The employing service may have to look to specialist HIV psychologists in other trusts and negotiations made as to whether the supervisory service can be supplied across trusts with payment for this this service made accordingly. If a psychologist is employed on a service level agreement from another trust, supervision could be provided by a psychological practitioner of a higher grade from this trust and would be included as part of the service level agreement as an additional cost [282].



### Appendix E: Suggested assessment and screening measures

### **Psychological screening**

Standardised screening tools with clinical cut-off scores that give indications of 'caseness' and level of severity of emotional distress.

Some are free to access, some may require purchase and some may require training for administration. Please note, risk assessment tools and scales and global risk stratification into low, medium or high should not be used to predict future suicide or repetition of self-harm and should not be used to determine who should and should not be offered treatment or who should be discharged (Self-harm: assessment, management and preventing recurrence, see [283]).

- Generalised Anxiety Disorder (GAD-7)
- Patient Health Questionnaire (PHQ-9)
- Clinical Outcomes in Routine Evaluation (CORE 10)
- Hospital Anxiety and Depression Scale (HADS)
- Impact of Event Scale-Revised (IES-R)

## Tools that can support exploratory clinical conversations and guide intervention choice

- HIV Patient-Reported Outcome Measures (PROMS)
- The Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS)
- The Wellness Thermometer

### **Cognitive screening**

The European AIDS Clinical Society (EACS) have proposed an algorithm for the assessment and management of reported cognitive problems which should be referred to [250].

BHIVA (2018) recommends the use of the following screening questions [284] when clinically indicated. An answer of "yes" to one or more may suggest the presence of cognitive issues (although not necessarily related to HIV):

- 1. Do you experience frequent memory loss? (e.g. you forget the occurrence of special events, even the more recent ones, appointments, etc.)
- 2. Do you feel that you are slower when reasoning, planning activities or solving problems?
- 3. Do you have difficulties paying attention (e.g. to a conversation, a book or a movie?).



NB If there are concerns regarding the oversensitivity of the questions, consider asking whether any of the issues identified impact on day-to-day function.

Two cognitive screening measures that have been validated on the HIV population are as follows:

- The Montreal Cognitive Assessment (MOCA)
- International HIV Dementia Scale (IHDS).

Clinical psychologists and clinical neuropsychologists may use a range of other cognitive screening and neuropsychological assessment tools in keeping with their training and expertise.



### **Appendix F: Training courses**

## Courses to support the development of psychological skills, communication and trauma-informed care

The following are examples of training courses that can be accessed by non-mental health clinicians to enhance psychological support skills to level 2 of the matched care model. If training is identified as a need, it should be included in personal development reviews, for the employing trust to support access to the training.

- Mental health training online and face-to-face [285]
- Psychological first aid [286]
- Suicide awareness training:
  - Applied Suicide Intervention Skills Training (ASIST) [287]
  - Samaritans one-day courses [288]
  - Understanding suicide intervention [289]
- Sage & Thyme a simple guide for listening to worried people [290]
- Trauma Risk Management (TRiM) [291]
- Trauma-informed approaches toolkit [292]

## Resources to support HIV cultural competence for individuals and organisations

- HIV Confident [199]
- NHS England Breaking Barriers in HIV Care [200]
- People First Charter [1]



### **Appendix G: FAQs**

#### What are the Standards?

This document sets out standards for psychological support, which should be available for all adults living with HIV in the UK. They aim to provide a framework of

care that services should aim to provide, either through specialist multidisciplinary teams with psychological practitioners embedded in the team, or by establishing robust pathways of care to psychological input.

### Why are standards needed?

- Owing to the high prevalence of psychological needs within the HIV population, it is important to ensure that all clinicians delivering care to people living with HIV are aware of and pay attention to psychological and cognitive issues.
- Without official recognition of these needs, clinicians may not routinely assess psychological need, meaning that people living with HIV will not be offered access to relevant support and interventions.
- The matched care model aims to offer evidence-based guidance on pairing different levels of needs with appropriate interventions delivered by suitably competent practitioners.
- If psychological needs are underestimated and health and economic benefits of interventions are not recognised, commissioners may fail to appropriately invest in psychological care provision.
- It has been evidenced that psychological care standards are not being consistently met across the UK, due to geographical disparity of resource. These Standards should act as a catalyst to improve responses to those needs and aid high quality, culturally competent and equitable access to psychological support.

#### Who should use the Standards?

These Standards are aimed largely at NHS and local authority funded clinical services, as this is where responsibility to meet physical and mental health needs should be held. However, the essential and valued work of community support

- services in the third sector is also central to the matched care model framework and can guide their input. The focus on NHS and local authority clinical services is not to exclude, but rather to protect community services from unfair responsibility of complex psychological care provision and to ensure they are not expected to do the work that should be commissioned by the NHS/local authority.
  - This document should be a key resource for service providers, commissioners, health boards and other local service planners, as well as for people living with HIV, to help
- define the minimum level of care expected from services. The Standards should be used in decision making regarding the availability and configuration of local services to ensure psychological support is appropriately planned and resourced.

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The Standards are intended to apply to all parts of the UK. While the systems and structures for planning and funding services differ between England, Scotland, Wales and Northern Ireland, all People Living with HIV are entitled to expect the same Standards of care.

### What is the scope of the Standards?

### In scope:

- Bringing attention to the importance of addressing psychological needs within HIV care
- Any form of support which is aimed at helping adults living with HIV to enhance their mental health and cognitive, psychological and emotional and wellbeing
- A framework to follow in terms of identified level of psychological needs and the competence required from different practitioners to meet those needs
- To guide commissioners and local service planners on what level and type of resources are required to meet the Standards

### Out of scope:

- Specific guidance regarding the types of psychological interventions offered
- Guidance regarding psychiatric care and mental health medication
- Specific guidance regarding teaching/training (although some examples are provided in Appendix E)
- Psychological support for children
- Psychological support for carers or other impacted people
- HIV prevention strategies (although psychological support for people living with HIV can reduce transmission)

#### How do services know they meet the Standards?

- Evaluation and audit can be used to measure whether the Standards are being implemented by services providing care for people living with HIV. This exercise may be undertaken on an individual service basis or coordinated across the local health economy or local HIV service network.
- Comparing service practice against best practice informs quality improvement, by highlighting gaps in or barriers to optimum care provision. Each standard contains auditable indicators to support the gathering of this data.
- Audit and evaluation should be required and resourced as part of the commissioning of services. Information gathered through this process can inform decisions on the cost-effective investment of resources through the recognition of improved outcomes.

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### **Appendix I: Acknowledgements**

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