


UPDATING THE STANDARDS FOR PSYCHOLOGICAL SUPPORT FOR ADULTS LIVING WITH HIV (2011)

RESULTS FROM A STAKEHOLDER CONSULTATION TO INFORM THE
REVIEW

BHIVA PSYCHOLOGICAL STANDARDS WORKING GROUP, MARCH 2023

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Contents

Executive Summary	2
Introduction	4
Methodology	9
Results.....	11
Overarching themes across all standards.....	12
Obstacles to implementation of standards.....	13
Suggested Additions to the standards.....	15
Individual standards.....	21
Standard 1: People with HIV should receive care which promotes their emotional, cognitive and behavioural wellbeing (psychological wellbeing) and is sensitive to the unique aspects of living with HIV.....	21
Standard 2: People with HIV should have access to a range of psychological support services appropriate to their needs	22
Standard 3: People with HIV should be engaged in the planning, delivery and evaluation of psychological support services.....	23
Standard 4: People with HIV should have timely access to information and appropriate emotional support following the diagnosis of HIV infection	23
Standard 5: People with HIV should have access to regular screening to identify if they have psychological support needs	24
Standard 6: People with HIV should have their psychological support provided by competent practitioners.....	25
Standard 7: People with HIV should have access to appropriate psychological support services that are coordinated within a managed framework	26
Standard 8: All psychological assessment and interventions for people with HIV should be based on the best available evidence	26
Discussion	28
Recommendations	31
References	33

Executive Summary

This stakeholder consultation was developed to inform an update to the Standards for psychological support for adults living with HIV published in 2011. Results demonstrate the clear progress in the biomedical model of HIV care has sadly not been matched by effective treatment for the mental health and wellbeing of people living with HIV.

While respondents recognised the relevance of the Standards to their practice, they expressed concern that diminishing budgets, fragmented provision and adequate staff resources were not available to deliver recommended care. This applies not only to specialist practitioners, but also to other key elements of the care package, such as social workers and third sector providers. All are essential to deliver psychological support effectively across all four levels of the Stepped Care model. Current lack of capacity is exacerbated by a lack of the time available to conduct even recommended annual screenings or staff training.

The current healthcare environment means that, with a few notable exceptions in urban settings, the care recommended in the Standards and framed by the Stepped Care model is simply not available with a clear lack in staff capacity and/or referral pathways. This means that they become increasingly dependent on the voluntary sector to fill the gaps, although both clinicians and the community recognise that this can be inappropriate and inadequate for complex cases. Specialist services are frequently under-funded, particularly if outside of large urban centres, and financial pressures have also led to a reduction in the budgets of community organisations.

The situation is compounded by the lack of a clear commissioning framework across the country and reductions in funding are exacerbated by the need to inform commissioning bids with auditable evidence of treatment benefit and outcomes. Best practice examples should be shared to help address this situation.

Training of all health professionals involved in an individual's care is in fact needed to avoid negative and stigmatic experiences which impact mental health outside of the clinic environment. In this context, stakeholders stressed the importance of co-production with people living with HIV to ensure cultural competence. The psychological support pathway from the point of diagnosis is crucial to subsequent health and wellbeing and should reflect the different needs of a wide range of ages and backgrounds.

Specialist HIV psychologists also highlighted the history of trauma experienced by a high proportion of people living with HIV, which underlines the importance of extending training to embrace the other healthcare professionals they will see.

At a time when person centred care and the need to address inequalities and social injustice are central to health policy, economic and structural fault lines must be addressed. Only then will we be able to meet the psychological needs of people living HIV to enable them to enjoy the rich quality of life promised by the huge advances in HIV treatment.

Introduction

Living with HIV can bring a range of complications. In addition to adjusting to managing a health condition, there can also be a psychological burden for many. Historically, this was rooted in the very real trauma of marked physical ill health, a high likelihood of death and the effects of pervasive HIV stigma, which compounded the complicated lives of often already marginalised groups (Nightingale VR, et al., 2011; Bird ST, et al., 2001; Bogart LM, et al., 2011, Dale SK, et al., 2016).

More recently, HIV has become a more manageable condition, however, some health- and medication- related issues are very present, and HIV stigma remains significant (Rodriguez-Penney AT, et al., 2013; Marzolini C, et al., 2010; Cambell T, 2020). It is also well-documented that pre-existing psychosocial vulnerabilities can increase the likelihood of a person acquiring HIV, and the circumstance of acquisition in itself can be traumatic (e.g. sexual violence and assault) (LeGrand S, et al., 2015) . Consequently, mental health issues remain significantly higher in people living with HIV when compared to the general population (Chaponda M, et al., 2017). This is due to factors such as stigma and discrimination in already marginalised populations; some also experience harmful side effects of treatment, including disturbed sleep; and there is a high prevalence of financial stress, adversity and trauma (Ayano G, et al., 2020; Tang C, et al., 2020; Watkins-Hayes C, 2014). The need for clinical mental health input, alongside the support from the HIV community, is acknowledged (BHIVA, 2018; BPS, BHIVA & MEDFASH, 2011).

In 2011, *The Standards for Psychological Support for Adults Living with HIV* were launched as a joint project between the British Psychological Society (BPS), the British HIV Association (BHIVA) and the Medical Foundation for HIV and Sexual Health (MEDFASH). The Standards aimed to promote the importance of establishing psychological assessment and treatment as an integral part of HIV care and have been used to develop the BHIVA Standards of care 2018 (Standard 6 Psychological care: People living with HIV should

receive care and support that assesses, manages and promotes their emotional, mental and cognitive well-being and health, and is sensitive to the unique aspects of living with HIV).

There are eight Standards, covering the different aspects of mental health care that any adult living with HIV in the UK should expect to receive. Each standard presents a rationale, quality statements and measurable and auditable outcomes.

The Standards are based around a four level, stepped care model (Figure 1), whereby increasingly complex psychological needs are met by suitably qualified and specialist practitioners. They consider referrals at all levels of need, integration with non-specialist services and the training and support of non-mental health clinicians from specialist HIV mental health practitioners to deliver psychologically informed care.

Figure 1: Recommended model of stepped care provision of psychological support

LEVEL	ASSESSMENT	INTERVENTIONS
<p>1</p> <p>Information and support</p>	<p>Understanding psychological needs of people living with HIV</p> <p>Understanding of risk of harm to self and others</p> <p>Recognising overt psychological distress</p>	<p>Effective provision of relevant information in accessible formats</p> <p>Supported self-help</p> <p>Signposting and referring to appropriate providers</p> <p>Response to overt distress</p> <p>Supportive communication and general psychological support</p> <p>Signposting self-management strategies eg books and computerised resources, newly diagnosed courses</p> <p>Peer support</p>
<p>2</p> <p>Enhanced support</p>	<p>Screening for psychological distress</p> <p>Screening for cognitive difficulties</p> <p>Assessment of risk of harm to self and others</p>	<p>Discussions aimed at acceptance and adaptation to living with HIV</p> <p>Signposting and referral to more appropriate services and peer support</p> <p>Education sessions around the nature of psychological and psychiatric problems and how to cope with them</p> <p>Brief interventions aimed at behavioural change eg sexual risk behaviour and substance misuse</p>
<p>3</p> <p>Counselling and psychological therapies (HIV-specialist)</p>	<p>Assessment and formulation of psychological problems</p> <p>Identification of psychiatric problems</p> <p>Screening for cognitive impairment</p> <p>Assessment of risk of harm to self and others</p>	<p>Counselling and psychological interventions based on explicit theoretical frameworks for specific psychological difficulties such as:</p> <ul style="list-style-type: none"> • moderate or severe anxiety • substance misuse • moderate or severe depression • psychosexual or relationship problems • sexual trauma/ PTSD <p>Interventions for cognitive impairment</p> <p>Psychological interventions based on explicit theoretical frameworks to develop and enhance positive psychological processes such as adaptive coping strategies which increase resilience</p>
<p>4</p> <p>Specialist psychological and mental health intervention (general or other specialist)</p>	<p>Psychiatric diagnosis</p> <p>Neuropsychological assessment</p> <p>Assessment and formulation of complex psychological problems</p> <p>Assessment for cognitive impairment</p> <p>Assessment of risk of harm to self and others</p>	<p>Specialist psychological and psychiatric interventions for severe and complex psychological problems, cognitive impairment, PTSD or co-morbid psychiatric problems such as:</p> <ul style="list-style-type: none"> • psychosis • severe depression • mania • eating disorders • personality disorder • cognitive impairment <p>and for specific situations such as:</p> <ul style="list-style-type: none"> • complex adolescent and family issues <p>Cognitive rehabilitation</p>

Since publication in 2011, there have been remarkable advances in HIV treatment, prevention and care in the UK. Most people receiving HIV treatment and who have an undetectable viral load have a life expectancy similar to the general population and do not pass on HIV. Rates of new infections are falling (PHE, 2020). The changing needs of people living with HIV, as well as the structural changes to NHS and social care delivery, mean that an update of The Psychological Standards is long overdue. Services have also adapted due to the COVID-19 pandemic, resulting in the introduction of different ways of working (APPG, 2020).

While there is much to celebrate, people living with HIV experience a higher level of poor mental health than the mainstream population (Kall M, et al., 2020) for a number of reasons, including ongoing stigma and because many already carry a history of trauma and adversity (Nightingale, 2011; Warner & Rutter, 2020). In recent years, despite treatment advances, specialist mental health services for people living with HIV have been cut, as has the provision of broader psychosocial support (Mulubale S, et al., 2018).

There is a need to recontextualise and revise the document in order to provide a current benchmark for optimum quality care. This project was therefore undertaken, commencing with a consultation to explore the opinions and experiences of the HIV community and HIV clinical care providers. The aim is to integrate the information gathered from relevant stakeholders into the revision of The Psychological Standards document.

It is the hope that the updated Psychological Standards, developed from the consultation, will bring together a wealth of experience and evidence regarding HIV and mental health, from personal and clinical perspectives. The updated Standards will inform and educate decision-makers, practitioners, and the wider population about the need for consistent and, wherever possible, specialist HIV mental health care provision.

Policymakers, healthcare practitioners and service commissioners now often simply treat HIV as a manageable long-term condition, failing to recognise the trauma of diagnosis and

the extent of poor mental health amongst people with HIV. Unless this failure to acknowledge HIV's complex impact on mental health is addressed, medical success in tackling the epidemic will be a hollow victory, and the target of zero new HIV diagnoses will not be achieved.

The aim of this document is to disseminate the findings of the stakeholder consultation that will be used to inform the review and updating of the psychological standards for care for adults living with HIV.

Methodology

Stakeholder invitation Key professional and third sector stakeholders (clinical HIV specialists, clinical psychologists and members of community organisations) were invited to contribute to represent HIV care in the delivery of psychological support. We are delighted that a number of specialist professional bodies, whose members have a role in providing psychological support to people living with HIV, were included in our working group.

Procedures The consultation was primarily carried out via electronic survey administered using Qualtrics™ and circulated to organisations in September 2021. Each organisation then decided how they would administer the survey. For organisations that could not access the electronic survey, a Microsoft Word (.docx) version of the questionnaire was circulated, which could be returned via email.

For the full questionnaire see Appendix 1. Survey questions resulted in a range of binary, ordinal and open-ended responses. Briefly, introductory questions explored the familiarity and use of the standards in daily practice. Thereafter, each standard was surveyed in turn to determine the importance, likelihood of achieving, barriers to achieving, inadequacies and use of auditable outcomes.

Data analysis Data collected represented the views of organisations. In the event there were multiple responses from one organisation, the responses were collated into one response. For binary and ordinal responses, the most commonly reported answer was taken. In the event of the responses having an even split, this was clearly labelled. All responses to open ended questions were retained for the analysis.

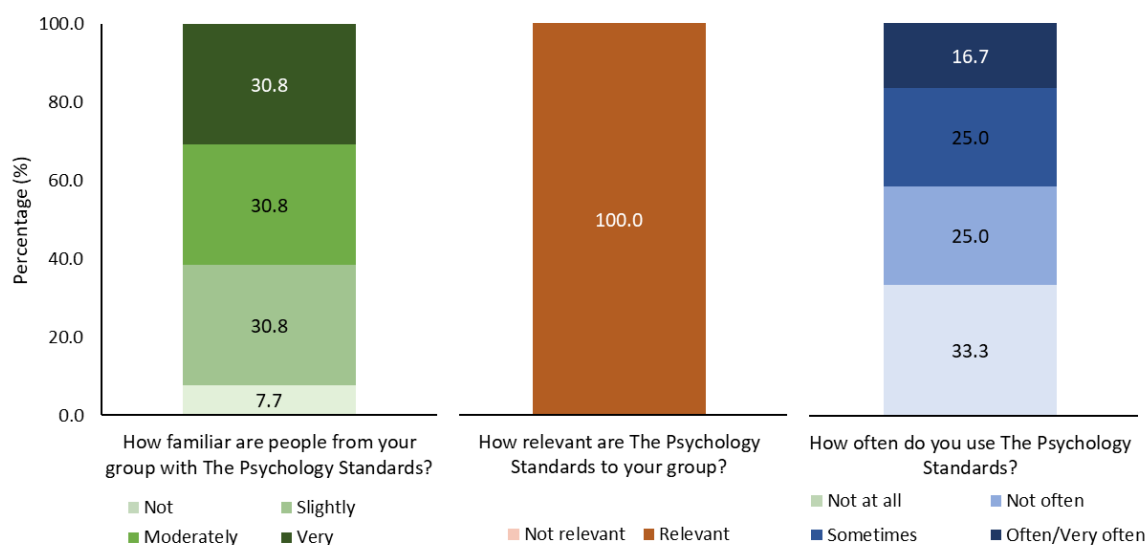
Binary and ordinal responses were summarised using numbers and percentages. Qualitative data from open-ended questions were inductively coded with a multidisciplinary team (HO, MC and SR) and summarised based on emerging themes. Upon analysing codes for individual standards, it became clear a number of themes were present across all standards. Therefore, overarching themes relating to the obstacles to achieving the standard and

recommended additions to the standards were first described before presenting the analyses of data relating to individual standards.

Results

In total, 35 questionnaires were returned/recorded. Three questionnaires were returned with no responses and were removed from further analyses. Ten organisations responded through the Qualtrics platform (four healthcare professional networks [two responses from one organisation were combined], four community organisations and one NHS trust). Three questionnaires were returned in Microsoft Word format (two from community organisations and one from a healthcare professional network). Nineteen individual responses from the British HIV Association (BHIVA) network were collated, which resulted in 13 organisations included in the analysis.

Figure 2: Stakeholder responses exploring the familiarity, relevance and use of the Standards for psychological support for adults living with HIV (n=12; one non-responder)



Although none of the groups suggested being extremely familiar with the standards published in 2011, four organisations (predominately healthcare professional networks) reported being very familiar with the document. Most organisations (8/13; mostly community organisations) felt they were moderately/slightly familiar with the standards with only one organisation suggesting they were not familiar with the standards.

While all organisations acknowledged the relevance of the standards to their group, approximately half (7/13) did not often use the standards to organise or access psychological care. Instead, clinicians who were part of healthcare professional networks or NHS trusts were more likely to consult the BHIVA standards of care (2018), NHIVNA Annual Health Review, European AIDS Clinical Society (EACS) guidance, CHIVA standards and National Institute of Health and Care Excellence (NICE) Guidance relating to mental health.

Amongst those organisations that actively use the standards, healthcare professionals suggested it is useful when informing annual objectives for mental healthcare (psychology services and service specification) which has allowed some areas to develop local mental health pathways. These standards have also been used as an advocacy tool, informing both healthcare staff and service users of what people with HIV are entitled to expect. However, apparent barriers to implementing the guidance may reflect the small number of organisations currently using the guidance.

Overarching themes across all standards

Figure 3: Obstacles to implementation and suggested additions

Obstacles to implementation of standards	Suggested additions to the standards
<ul style="list-style-type: none"> • Political will • Lack of clear commissioning framework • Geographical disparity in care • Funding • Staffing • Time • Training 	<ul style="list-style-type: none"> • Prioritise mental health and wellbeing • Person-centred care • Address inequalities and social injustice • Co-design/co-development of services • Peer support • Referral pathways • Training • Information/ resources • Best practice examples

Obstacles to implementation of standards

Political will It was noted that mental health was not included in the HIV Service specification. Organisations believed that as long as HIV was seen as a manageable biomedical condition, the psychological impact of HIV would not be prioritised. It was thought that the emotional wellbeing of people with HIV should be on the agenda for NHS England, and therefore it should be the responsibility of service providers/commissioners to build this into the service specification and implement it accordingly.

‘Too often HIV remains seen through a biomedical lens through which psychological needs are not given parity of attention’

Lack of clear commissioning framework it was noted that, to date, psychological support is not included in the design, development, and provision of all HIV treatment, thus resulting in a fragmented model of care. This lack of a consistent and coordinated framework for commissioning services to address mental health amongst people with HIV means services face great challenges coordinating seamless pathways between provision in health, social care and the voluntary sector.

‘Psychological support is not included in the design, development and provision of all HIV treatment and care services across local areas, and services are not coordinated within a managed framework’

Geographical disparity in care There was widespread concern about the lack of a consistent approach to mental healthcare across the country, so that the availability of comprehensive support and treatment was a ‘postcode lottery’. Individuals diagnosed with HIV in low prevalence or remote areas, had little or no access to mental health services. This was particularly apparent where there was no NHS in-house provision of specialist

psychological support. This left services inappropriately relying on the voluntary sector for mental health care, with no clear pathways to access mental health services within the NHS.

‘The types and level of psychological support available to people living with HIV is a postcode lottery, and pathways between them are often non-existent’

Funding Issues around lack of funding for services were reported by all sectors. The current model runs on fragmented funding, which fuels the geographic disparity mentioned above. Insufficient funding for the provision of specialist mental health care through NHS HIV service should, in theory, lead to greater funding and commissioning for third sector HIV organisations. However, there is no specific funding to ensure current work is properly supported.

‘There is no specific funding for the counselling service for example. Very dependent on having the right person/people with sufficient funding/ resource.’

Staffing It was noted that implementing the standards in full would require a significant level of staff resource (and funding). Over recent years, many clinics have lost access to specialist support or skilled staff, including psychologists, social workers, third sectors workers and support staff, who together provide psychological support across all four levels of the stepped care model.

‘Many clinics have lost access to specialist support from psychologists, social workers, third sector workers, or support staff over the years.

Psychology Standards in full would require a significant level of staff resource.. that would impact the provision of other services’

Time All organisations said time was a barrier, with healthcare professional networks reporting that large/busy clinics with high staff turnover and funding constraints find it difficult to prioritise the necessary time for mood screening at annual reviews. In addition, clinics reported finding it hard to allocate time to ensure continual professional development because of workforce changes, and to support training with ongoing supervision. It was noted that these are equally important, although challenging to deliver, within already busy clinics.

‘Busy clinics with relatively high staff turnover / high staff sickness will find it difficult to prioritise time to.. carry out minimal mood screening at annual reviews’

Training It was proposed that a basic level of training on HIV, HIV stigma and talking about sex should be provided to all staff caring for people with HIV. However, where care is provided outside of the HIV clinic is it highly unlikely that staff will have received training on HIV, which itself can impact the mental health of people living with the condition. In addition, community organisations indicated the standards do not provide clarity on who should provide training, or what the training programme should include, at each level of the stepped care model.

‘Where care is provided outside of the HIV clinic is it highly unlikely that staff will have received training on HIV and its impact on mental health’

Suggested Additions to the standards

Prioritise mental health and wellbeing There was a sense that the standards should shift focus from psychological difficulties to psychological wellbeing and prioritising good mental health. Therefore, it would be useful to articulate that these standards are relevant to / non-clinical levels of emotional distress requiring support, as well as to psychological difficulties

requiring specialist services. In order to ensure this level of understanding within HIV specialist services, psychologists felt they should be appropriately represented at a leadership level.

‘Clinicians should be proactive in asking about emotional wellbeing and know what supports this for each individual. ..therefore be about ongoing psychological health rather than only psychological difficulties.’

Person-centred care Community organisations reported that services do not capture the culture/background of people engaging with them. The standards therefore require explicit recognition of the need for representatives of all communities living with HIV to address inequalities in access to services and outcomes between different groups. Therefore, to ensure cultural competence, people living with HIV of different cultural backgrounds should be included when designing and delivering services.

The psychological standards need to encompass person-centred and holistic approaches to meet the needs of the wide range of cultures and ages of people living with HIV. There may also be a need to offer specialist expertise and/or signposting for additional social, emotional and health complexities (e.g. chemsex, comorbidities, and complicated/diverse lifestyles).

‘More explicit recognition of the need for engagement to include representatives of all communities living with HIV – this is vital to address inequalities in access and outcomes between different groups and to ensure that services are culturally competent’

Address inequalities and social injustice Attention was given to how people living with HIV often experience a marginalised identity in conjunction with the diagnosis. Healthcare professional networks and community organisations recommended each standard address

multidimensional inequalities and social injustice (particularly issues around stigma, discrimination, welfare cuts and adherence issues) which many people living with HIV experience. They are known to impede access to, and effectiveness of, psychological support (e.g. for women, members of LGBTQI groups, refugees and asylum-seekers).

'More attention is needed to issues of multidimensional inequalities and social injustice which many people living with HIV experience around diagnosis.. which therefore currently limit access to and effectiveness of psychological services at diagnosis'

Co-design/co-development of services Community organisations thought the design and implementation of mental health services need to integrate the voice of people with HIV through co-production rather than consultation. The psychological support pathway from the point of diagnosis needs to be explicitly informed by the experiences and knowledge of people living with HIV, therefore recognising the need for engagement to include representatives of all communities living with HIV. This is vital to address inequalities in access and outcomes. It was proposed that to ensure sustainability and involvement, patient participation groups can provide an option for people living with HIV to get involved.

'Formulation, implementation, evaluation and development of comprehensive psychological care needs to start from people living with HIV's own knowledge, understanding and priorities'

Peer support All community organisations have petitioned for peer support to be positioned as a central part of each standard given that it is a form of psychological care that is heavily relied upon. It was felt that currently peer support is presented more as a 'nice-to-have' than fundamental - something which should be universally available and central to effective HIV care. Competent peer support can occur at all levels of mental health need. However, for

higher levels of complexity, it is imperative it is in collaboration with appropriately qualified practitioners. Nevertheless, all people with HIV should be aware of the peer support available and know how to access it.

Unfortunately, the pathways for becoming involved in peer support are not clear. The respondents called for clarity in the definition of peer support, how/where peer support could be accessed and information on pathways to becoming a peer support worker.

'Peer support needs to be a central part of each standard, not just, as at present, a late or marginal item in a list of services within some standards'

Referral pathways It was noted how the lack of political will and commissioning pathways (as described earlier) has meant there are no clear pathways to access treatment following screening for mental health. The consideration of referrals, and the development of referral pathways, should explicitly include non-clinical and non-HIV specific services. This is particularly important as current informal systems run by people living with HIV are not recognised or integrated into the specification of mental health services available to people with HIV. It is important to the respondents that all HIV services have clear referral pathways into mental health care at all levels of need according to the stepped care model.

As already said, although it is accepted that specialised HIV mental healthcare should be accessible for all who need it, limited resources have meant this load is often carried by the voluntary sector. This is adding pressure to already under funded community support services and, placing inappropriate responsibility on peer support mentors to manage complex mental health needs. It was advocated by both clinicians and service users that referrals to outside agencies or voluntary sector services should be regulated and evaluated.

‘Guidance on enhancing referral pathways between specialist HIV psychology services, generic mental health and wellbeing services’

Training It was stated that service providers must be prepared to address mental health and wellbeing in consultations or annual reviews across the healthcare system. Therefore, all members of staff should have a minimum level of training. Respondents have asked for the standards to clarify the gold standard knowledge that should be accessible for all HIV-related and non-HIV staff (e.g. GPs, health advisors etc) for each of the steps of care.

Specialist HIV Psychologists highlighted that a high proportion of people living with HIV have a history of trauma or complex trauma. It is therefore essential for all members of staff to be trained in a trauma-informed care approach.

‘Training is needed to ensure that all staff feel comfortable asking questions about psychological issues’

Information/resources It was highlighted that there is a need for a diverse range of information/resources to take account of cultural, linguistic and literacy requirements, to ensure everyone knows about the psychological support available and how to access it. Availability of up-to-date information about the range of support and treatment available to people with HIV will allow individuals to make patient-centred decisions about the appropriate level of care.

Clinicians mentioned that infection control procedures around COVID-19 have unfortunately made it more difficult to use resources promoting psychological wellbeing, such as leaflets and posters. The response was to consider introducing more information in digital format.

‘Reference to the need for information/resources to take account of cultural, linguistic and literacy needs should be included in the recommendation itself’

Best practice examples Respondents believed it would be beneficial to have examples of best practice or gold standard implementation guidance. This was crucial for service planning, commissioning of specialised HIV mental health services, and developing/managing referrals to third party organisations.

‘Consider best practice examples for involving service users in service planning, commissioning and evaluation’

Individual standards

While all organisations agreed that each standard was important, many reported they were uncertain, or felt it was unlikely, that they could achieve them. Individual obstacles and actions for each standard are outlined below:

Standard 1: People with HIV should receive care which promotes their emotional, cognitive and behavioural wellbeing (psychological wellbeing) and is sensitive to the unique aspects of living with HIV

It was noted that HIV and mental health are widely stigmatised and interact with cultural identity in different ways. In addition to the obstacles reported previously, organisations suggested reduced face to face services, and lack of recommended continuous measurement/assessment tools for psychological wellbeing, were barriers to achieving this standard.

It was said that although psychological wellbeing should be discussed in all healthcare settings, there is no clarity regarding the setting in which it should be taking place. People with HIV should be able to talk about their emotional health to all healthcare professionals (including nurses, doctors, other staff). Therefore, it is important that this standard clarify that all clinicians should be proactive in asking about emotional wellbeing.

For service users, it was stated that the wording of this standard read as a general statement and there was no clarity on actionable steps. It was proposed that the language could encompass a more person-centred approach by adding 'as experienced by each individual'. In addition, service users believed that there should not be an over reliance on 'tick box' screening tools (ie. PHQ or GAD), as these can lead to conversations which are not genuine.

Healthcare professionals thought it would be helpful if this standard clarified the difference between non-clinical levels of emotional distress vs. psychological difficulties that require specialist services. They also reflected on the importance of identifying a strategy to address

stigma (e.g. an anonymous method of reporting experiences of stigma in healthcare settings). Finally, clinicians suggested that this standard should set the tone for the range of consultation styles now available, and recognised the role of virtual consultations in this new era of digital healthcare.

Standard 2: People with HIV should have access to a range of psychological support services appropriate to their needs

It was noted that due to the absence of mental healthcare in the HIV service specification, there is currently only fragmented funding for mental health services, with no access to additional funding to address the gaps. Continuing cuts to public health spending and a lack of clear commissioning for mental health services have resulted in the decommissioning of voluntary sector HIV services, traditionally alternative providers, as well as sources of peer support.

There was a sense that some people living with HIV may have needs that are too complex for generic services, but their condition is not considered 'severe' or 'high-risk' enough to meet the threshold for secondary care. Generic mental health services are therefore not currently equipped to support the mental health needs of people living with HIV.

Organisations expressed the opinion that commissioners should actively fund basic psychological care for all people with HIV and clear commissioning guidance is essential to achieve comprehensive psychological support. Where pathways are left to be locally defined it was suggested examples of best practice and audits or cost savings should be included in the standards to help practitioners to build a case to commissioners for funding specialist mental health services linked to HIV services.

Community organisations proposed each HIV service to have a designated, competent clinical lead for psychological support, as service users have stated that many people do not trust non-specialist services in terms of sharing their diagnosis.

Standard 3: People with HIV should be engaged in the planning, delivery and evaluation of psychological support services

In the data, there were three clear obstacles (in addition to those outlined previously) to achieving this standard: (i) lack of recognition of the expertise and experience of people living with HIV so that their voices are not heard when designing and delivering mental healthcare; (ii) there is currently no system in place to develop an effective strategy for planning and evaluating mental health services for people with HIV. This is required to ensure future services are efficacious and cost-effective and (iii) when attempting to engage people with HIV, the structural barriers present require teams to follow time consuming recruitment and management procedures set by trusts, which does not allow timely results.

In order to address these, community organisations called for clarity on the definition of 'engage' – what does this look like? What does this mean? This is especially important as peer support services play a substantial role in planning, delivering and evaluating services, but are not recognised or integrated. In addition, some members of community organisations reported attempting to engage with no fruitful outcome. Although there should be more explicit recognition of the need for engagement to include representatives of all communities living with HIV, there are no clear pathways for becoming involved. It was suggested that healthcare professionals should invite voluntary organisations to help develop guidance on involvement for the standard.

Standard 4: People with HIV should have timely access to information and appropriate emotional support following the diagnosis of HIV infection

Timely access to care was thought to be impeded by many of the factors discussed previously. These include lack of standardised commissioning and referral pathways, so that many people newly diagnosed with HIV were unsure where they could access either information or emotional support. The core of this problem is in lack of funding, reduced staffing and limited time for training.

It was recommended that this standard be updated to reflect the wider range of testing (e.g. self-testing, non-traditional settings). People accessing testing outside of traditional settings should be considered in the standards going forward, with clear pathways for linkage to care developed. It is also important to consider how an HIV diagnosis is given. The nature of the immediate support offered during that interaction can make the difference between whether someone is deeply traumatised or able to move forward, armed with accurate and positive information. It was proposed that the standards should outline what support and information is to be provided at the time of diagnosis in various accessible formats, and where this could be found, and from which services (specialist vs. general services).

It was also thought that the Undetectable=Untransmissible (U=U) message should be integrated at diagnosis as this can have a huge positive impact on mental health. There are recommendations that peer support should be factored into the process here as it is both needed and effective at diagnosis complementing the information and treatment provided by clinicians.

Standard 5: People with HIV should have access to regular screening to identify if they have psychological support needs

It was advocated that the importance of mental health and wellbeing of people with HIV must be integrated into the priorities at annual review. The lack of a standardised recommended screening tool and clear pathways to care were reported to be obstacles in achieving this standard.

Healthcare professionals have asked for clear evidence-based guidance on screening, including screening for QoL, psychological distress, trauma, mental health need, drug and alcohol use, self-harm, suicide-risk and other risk-taking behaviours.

Respondents asked that the standards reinforce that screening and mental health assessments should be carried out annually. This opportunity should be used to link to other guidance in a culturally appropriate and holistic manner, not just as a tick box exercise.

Training is needed to ensure that all staff are equipped to ask questions about psychological issues.

From the service user perspective, individuals were unsure whether they had been screened. This indicates either that a screening has perhaps not taken place, or that there is a need to clearly explain the screening process and its results. Service users suggested they would like to be asked general wellbeing questions, such as "how are you feeling today/this week?".

Standard 6: People with HIV should have their psychological support provided by competent practitioners

There were reports of significant geographic disparity in the support available due to the size/location of the clinic. Although reduced funding in lower prevalence areas means fewer staff, training was cited as the most complex obstacle when assessing this standard. There were two reasons why: (i) People with HIV often experience feeling stigmatised or treated poorly by healthcare professionals. It is thought that generic services have a low level of HIV-specific competence and therefore lack basic training on HIV, HIV stigma and talking about sex. This should be available to all members of staff in generic services. However, there was also a sense that (ii) the standards lack clarity on who should provide training to practitioners or what the training programme should include at each level of the stepped care model.

In response, organisations have proposed that a list of gold standard training content/courses be published along with the guidance for each of the steps of care.

Clinicians also recommended that these be labelled 'required competencies' across each level of need rather than as a single list of 'minimum competencies' – which has previously been interpreted as the bare minimum. The idea of HIV 'champions' in generic services was also suggested in the responses.

Standard 7: People with HIV should have access to appropriate psychological support services that are coordinated within a managed framework

Due to psychological support not being included in the design, development and provision of all HIV treatment, services are not coordinated within a managed framework. The greatest challenge identified in this setting is coordinating services between health, social care and the voluntary sector. This is dependent on having the right person/people with sufficient funding/resource deploying a service in your local area. The biggest obstacle was therefore viewed as people working in silos and not looking at the bigger picture of reducing the burden of poor mental health in this population.

Therefore, organisations appealed to NHS England to consider psychological support to form a part of the national service specification for HIV services. All HIV services should have access to a psychologist/level 4 mental health professional on their multidisciplinary team (MDT). Healthcare professionals urge the update to the standard to share any good examples of MDT clinical networks that have worked for services in the past.

Self-referral is available in primary care and the voluntary sector. Clinicians wondered whether this could be expanded to HIV psychology services. It was acknowledged that this would need to be considered carefully to ensure that people living with HIV were aware of pathways and confidentiality parameters.

Standard 8: All psychological assessment and interventions for people with HIV should be based on the best available evidence

It was recognised that evidence of effectiveness of psychological interventions for people living with HIV was extremely limited. This suggests the current landscape of treatment and management are extrapolated from wider guidance. However, it was noted that, in practice, commissioning decisions are not always evidence-based – for example, peer support having been decommissioned.

Clinicians advised it would be good for the standards to highlight current research and evidence of effectiveness and good practice in regard to mental health. It was also considered important to commission well-resourced services that can allocate time to producing clinically relevant research, audit, and quality improvement projects. This would help by adding to and updating the evidence-base. Therefore, it was suggested that interventions should be evaluated, and feedback should be requested from people who access them.

There was acknowledgement that, although evidence exists regarding peer support, it is collected in ways not usually recognised in the hierarchy of evidence in evidence-based medicine. There was a clear sense from both community organisations and healthcare professional networks that evidence from peer support/research from people living with HIV needs to be given weight within evidence-based practice.

Discussion

Prior to the introduction of the psychological standards for adults living with HIV in England, there was little support and guidance when navigating the key aspects of psychological care for this population. The results from this report give newfound motivation to continue and develop this mission of equitable access to psychological care for all people living with HIV with some key learning points.

Although we have highlighted the continued importance of such a resource today, with all participating organisations reporting the relevance of the standards, this was coupled with the challenge of how to use or implement the standards.

This was particularly evident when assessing the use of auditable outcomes (auditable outcomes were included with the publication of the original standards of psychological care). No organisations reported the use of these, and only one national audit using the standards has been identified (led by NHIVNA). Of the 1,446 case notes in this audit (from 52 sites), information regarding psychological well-being was not documented for 547 (37.8%) of the cases. There was no information about the disparity in clinics, however only 13 (25.0%) services reported having a psychological support policy and 21 (40%) reported having no mental health professional as member of the team (NHIVNA, 2015).

National recommendations around the provision of psychological support for people with HIV have been updated in the BHIVA Standards of Care for people living with HIV, which now include a consensus regarding the assessment, annual monitoring for psychological problems, and how to use a stepped-care approach to enable access to appropriate support services (BHIVA, 2018).

Results from the BHIVA national audit 2017 assessed whether services adhered to standards when providing psychological support. Although they did not use the auditable outcomes from the Standards of Psychological Care for Adults living with HIV, this audit

included information representing approximately 5% of people with HIV in the UK (4486 people with HIV across 119 sites). Similar to the NHIVNA audit, routine assessment of psychological wellbeing was reported to have been recorded for 2949 (66.0%) individuals. Rates varied widely between sites, from 10% to 100% [median: 62%; interquartile range (IQR): 49–90%] which may be a result of themes reported in our obstacles to implementation of standards (i.e. funding, staffing and training) (Parry S, et al., 2019).

Despite BHIVA recommendations, only 49.1% of sites reported having an identified clinical lead for psychological support, 52.7% sites had documented care pathways for mental health and 63.4% were able to provide specialist mental health support within their own service. We found that where there was no NHS in-house provision of specialist psychological support, services were left inappropriately relying on the voluntary sector for all mental health care with no clear pathways to access mental health services within the NHS. Though this is not ideal, there is a need to acknowledge the reality of this and endeavour to provide support to these organisations to ensure that there is safe provision of psychological support. Although it was promising that >80% of sites were able to refer directly to specialist mental health, there was limited detail regarding whether the referral services were designed for people with HIV, or generic mental health services which we identified as a barrier to culturally competent psychological care for this population (Parry S, et al., 2019).

Consistent with current literature, both audits reported a high number of people living with HIV were deemed to have some need for psychological support (NHIVA: 43.4%; BHIVA: 37.1%). There is an extensive literature about the effects of past trauma that creates vulnerability to the acquisition of HIV, affects how individuals cope with the condition once acquired and has an impact on individuals' ability to be resilient in the face of multiple challenges over a lifespan (Nightingale VR, et al., 2011; LeGrand S, et al., 2015; Watkins-Hayes C, 2014).

Interestingly, BHIVA reported levels of identified need were higher at sites with a clinical lead and/or routinely using a standardised assessment tool/questionnaire, which might suggest the burden is underestimated in clinics that cannot offer routine assessment due to lack of resource. Evidence for this unmet need can be difficult to collect, report and synthesise, but we consider that an annual health review (as recommended by NHIVNA, 2019) could include and record questions about psychological care needs to consistently gather evidence about such needs in order to influence local service provision.

What became apparent in this consultation with stakeholders was that there was a clear desire for the standards to provide guidance on how best to implement psychological care into HIV services. Unfortunately, this is not within the remit of the Standards, as currently there remains a lack of evidence regarding this aspect of care to inform the development of the guidance document. However, It is the desire of this working group to continue to advocate for the development of this evidence through the recommendations, as a result of this consultation. We believe that updating the standards will go some way to create a benchmark for future evidence generation.

Recommendations

The results of the consultation have been used to inform the following recommendations.

These recommendations aim to encompass the main themes arising from the stakeholders who participated and are specifically to guide the revision of the psychological standards document.

The updated standards should aim to:

- Draw attention to the need for political will and clear commissioning guidance to achieve equity of psychological care across the UK.
- Link to other standards and guidance documents relevant to the provision of care for people living with HIV
- Advocate for in-house specialist psychological and mental health support, where practitioners are based within medical MDT's.
- Ensure that there are mental health clinical leads (for each service, or across regions) to co-ordinate service delivery and ensure that all levels of psychological need are met with appropriate support.
- Specify psychological training requirements for each level of need based on the stepped care model.
- Describe competency levels required to deliver psychological support at each level of need
- Promote person centred care as essential and integrate this with acknowledgement of the importance of trauma-informed approaches.
- Focus on wellness, as well as distress and offer guidance around what constitutes clinical levels of distress.
- Provide frameworks and guidance for distinguishing when generic versus specialist support is required.

- Acknowledge the role and importance of peer support throughout the document and specify how this would be integrated and supported at each level of the stepped care model.
- To include the input of people with lived experience at all levels of service design and development.
- To define what service user involvement means and include best practice examples for addressing structural barriers to involvement.
- Establish clearly defined pathways to psychological support, based on available national resources.
- Provide information relating to screening tools and frequency of screening, giving an explicit structure around this
- Advocate cross service working and integrated care to meet the complex and changing needs of people living with HIV.
- Include actionable steps and best practice examples to enhance usability through tangible information.
- Acknowledge the new context of HIV throughout the document and how this pertains to the provision of psychological care. This will include paying attention to factors such as U=U, remote working, wider range of testing methods (e.g. self-testing) and how they are associated with linkage to care.
- Point to the importance of research evidence relating to HIV and mental health and propose that services are suitably stocked to support such research activity.

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