British Psychological Society

British HIV Association

Medical Foundation for AIDS & Sexual Health

Standards for psychological support for adults living with HIV

NOVEMBER 2011

Endorsements

The *Standards for psychological support for adults living with HIV* were produced in partnership and endorsed by:

British Psychological Society (BPS)
British HIV Association (BHIVA)
Medical Foundation for AIDS & Sexual Health (MedFASH)

British Association for Counselling and Psychotherapy (BACP)
British Association for Sexual Health and HIV (BASHH)
National AIDS Trust (NAT)
National HIV Nurses Association (NHIVNA)
Royal College of General Practitioners (RCGP)
Royal College of Nursing (RCN)
Royal College of Psychiatrists' (RCPsych) Faculty of Liaison Psychiatry
Society of Sexual Health Advisers (SSHA)

Contents

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Foreword

We are delighted to publish these standards for psychological support for adults living with HIV, the first time such a document has been produced in the UK. A wide range of service providers across health, social care and community organisations play a crucial role in the provision of psychological support for people living with HIV. These standards, developed through multidisciplinary and multi-sector collaboration, set out a clear framework to guide practice in this complex field.

Psychological health and wellbeing are key components of health and quality of life for everyone. However, despite significant medical advances in HIV treatment, people living with HIV experience significantly higher rates of psychological difficulties than the general population. This has a major impact on quality of life, complicates clinical care, compromises physical health outcomes and heightens the risks of onward HIV transmission. The standards therefore focus on the promotion of mental health and wellbeing for all adults living with HIV, as well as the early detection of psychological difficulties and the provision of appropriate interventions for those who need them.

These standards are in line with the principle of mainstreaming mental health, as set out in *No health without mental health,* the Government's mental health strategy for England. They represent current good practice which we believe people living with HIV should expect from their care providers. Throughout the standards, the person living with HIV is placed at the centre, whatever their level of need.

The recommendations in this document offer real opportunities for preventing avoidable ill-health and reducing associated costs to the NHS and local authorities. At a time when financial constraints are threatening the continuation of some services that deliver psychological support for people with HIV, these standards provide the rationale for evidence-based investment. They are an essential resource for commissioners of health and social care.

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Summary of recommendations

Standard 1: promotion of mental health and psychological wellbeing

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

1.1.1 Psychological wellbeing on the agenda

PLWH should be given the opportunity to discuss their psychological wellbeing with the professionals providing their health and social care.

1.1.2 HIV-sensitive care

PLWH should receive confidential, non-stigmatising care that is informed by an understanding of the unique HIV-related factors affecting psychological wellbeing.

1.1.3 Information to promote psychological wellbeing

During their contact with health and social care services, PLWH should be provided with information and resources promoting their psychological wellbeing, such as leaflets, posters and websites, as well as access to patient/service user representatives and peer support.

Standard 2: comprehensive psychological support services

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

2.1.1 Assessment for psychological support

All PLWH should be assessed for the appropriate level of psychological support to meet their needs.

2.1.2 Stepped care model

The stepped care model (see page 22) should be used to plan and enable access to the psychological support services needed by each individual at levels 1, 2, 3 or 4 (see Introduction and Standard 7).

2.1.3 Access to interventions

All PLWH should be provided with level 1 psychological support that includes information, signposting and supportive communication. They should also be provided, according to agreed referral criteria, with subsequent levels of more complex intervention when indicated through psychological and cognitive screening and assessment.

2.1.4 Timely access

Access to interventions should be timely, according to identified need. Where screening or clinical observation identifies a serious and immediate risk of harm to self or others, PLWH should be referred immediately to emergency mental health services (level 4). A pathway needs to be locally defined for access to these services. PLWH referred less urgently for specialist psychological support (level 3) should be seen within a maximum of three months.

Standard 3: engagement of people living with HIV

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

3.1.1 Engagement in service planning and development

PLWH should be consulted about the psychological support services they might wish to attend as well as the one(s) they do attend.

PLWH should be consulted and actively involved in the design, redesign and development of psychological support services.

Inclusive frameworks to engage PLWH, reflecting their diversity, should be developed across all services providing psychological support.

3.1.2 Engagement in service delivery

As part of psychological support service delivery, PLWH should play a role in the provision and dissemination of information about HIV and HIV services to other PLWH, as well as providing peer support, advice, advocacy and means of engagement.

3.1.3 Engagement in service evaluation

PLWH should be provided with opportunities for feedback on psychological support services as part of service evaluation, to inform service management and local policy.

The development, collection and reporting of outcome measures for psychological support services should include involvement of PLWH to ensure that these capture both clinical outcomes and user experiences.

3.1.4 Support for engagement of PLWH

PLWH who are involved with service user activities should be provided with opportunities to update and develop their knowledge and skills in order to maintain effective involvement with professional services and to ensure a consistent approach to psychological support.

Standard 4: support at the time of diagnosis

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

4.1.1 Support and information at the time of diagnosis

At the time of their HIV diagnosis, all PLWH should be offered one-to-one emotional support by the practitioner giving them the test result. If after the initial post-test discussion more in-depth counselling or other support is urgently needed, rapid referral to an appropriate provider should be offered if this is beyond the competence or capacity of the testing provider.

Immediately relevant information about HIV infection and its implications should be given verbally at the time of diagnosis and backed up by provision of, and signposting to, written information as appropriate.

Regardless of where testing takes place, all practitioners providing test results and emotional support at the time of diagnosis should have the competence to do this, with access to relevant training and professional support.

4.1.2 Referral for psychological support following diagnosis

Clear local policies and pathways for post-diagnostic support and referral should be in place and apply to all settings offering HIV testing. All newly diagnosed PLWH should be offered psychological support from practitioners with expertise in HIV at the earliest possible opportunity, preferably within 48 hours and certainly within two weeks of receiving the test result.

Standard 5: identifying psychological support needs

People living with HIV (PLWH) should have access to regular screening to identify if they have psychological support needs.

5.1.1 Screening for the presence of psychological difficulties

PLWH should have access to screening for the presence of symptoms of depression, anxiety, drug and alcohol misuse, acute stress disorder and risk of self-harm within the first three months of receiving an HIV diagnosis. It is essential for pathways to be in place for further assessment following screening for those who need them.

5.1.2 Screening for the presence of cognitive difficulties

PLWH should have access to screening for cognitive difficulties within the first three months of receiving an HIV diagnosis.

5.1.3 Repeat screening

PLWH should have access to repeated screening following events which are known to trigger or exacerbate psychological distress or cognitive difficulties, and otherwise on an annual basis.

5.1.4 Referral following screening

PLWH whose screen suggests significant difficulties should be offered referral to a suitably competent practitioner for further assessment.

Standard 6: competence to provide psychological support

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

6.1.1 Competence to provide psychological support

All individuals requiring psychological support should have this provided by skilled practitioners who have been appropriately trained and have demonstrated the necessary competencies.

6.1.2 Assessment of competence

Required standards, roles and competencies should be defined for all practitioners providing assessments and interventions across the spectrum of psychological support for PLWH. Agreed mechanisms should be in place for the assessment of competence according to these benchmarks.

6.1.3 Maintaining competence

Services providing psychological support for PLWH should ensure that their practitioners can demonstrate competence on an ongoing basis and should make provision to support the maintenance of competence through training, continuous professional development (CPD) and supervision.

Individual practitioners have a responsibility to ensure that they have received training and attained the required competencies before undertaking assessment or interventions to meet psychological support needs. They are also responsible for maintaining their competence on an ongoing basis but should be supported in this by their employing organisation.

6.1.4 Training

Specialists providing level 3 and level 4 psychological support (see stepped care model on page 22) should normally provide training, supervision and CPD for practitioners operating at levels 1 and 2. Specialists should also receive training, supervision and CPD as appropriate to their role and profession in order to develop and maintain competencies at that level.

Accredited training courses in communication skills should be available for all practitioners who are working with PLWH. Advanced communication skills training should be undertaken by those who frequently have to break significant news including HIV test results, explain complex formulations or discuss distressing issues.

Training for the skills and competencies to deliver psychological support to PLWH should be provided to augment generic training for psychological screening, assessment and interventions.

6.1.5 Required competencies

Competencies are required by practitioners providing psychological support at levels 1, 2, 3 and 4 in line with the stepped care model (see page 22).

In addition to generic competencies required by practitioners for their particular role and professional qualification, all practitioners providing psychological support for PLWH should have a demonstrable minimum set of competencies consisting of awareness and understanding about HIV and its impact on those living with the disease, including the cultural dimensions.

Standard 7: coordination of psychological support

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

7.1.1 Service design

Psychological support should be included in the design, development and provision of all HIV treatment and care services across a local area. A coordinated range of psychological support interventions should be offered across the spectrum of local providers.

7.1.2 Pathways of care

Clear pathways should be developed between services providing HIV clinical treatment and care and those offering psychological support. Pathways should be explicit, agreed and adopted by all HIV clinical service providers.

Psychological support should be delivered through a network of providers with different levels and types of expertise in psychological issues for PLWH (see stepped care model, page 22). Services should be planned to provide seamless integration across levels of psychological support and across providers, including transitions from services for families and young people to those for adults.

A pathway enabling PLWH to self-refer into psychological support services should be established.

Pathways should also be in place to ensure the availability of psychological support at all levels from practitioners with specialist expertise in HIV.

Service providers should establish pathways to ensure PLWH can access specialist level 3 and level 4 support as and when they need it. Emergency psychiatric services should be available when required for PLWH with severe mental health problems in and out of normal working hours.

7.1.3 Leadership and collaboration

The provision of psychological support for PLWH should be strategically planned and coordinated across all relevant local providers. Such coordination requires collaboration across organisational and professional boundaries with clearly defined and accountable leadership and management arrangements. This may be achieved through HIV service networks or clinical networks where these are in place.

Clinical leadership of psychological support for people who use HIV treatment services should be provided by practitioners who have level 4 psychological support skills with particular expertise in HIV. Clinical leads should be part of the multidisciplinary clinical and management teams of services providing HIV care, collaborate with the professional leads of other local services providing psychological support for PLWH (eg social care and community support) and work closely with commissioners.

7.1.4 Service provision

Commissioners, clinical leads and other relevant stakeholders should work together to ensure that high quality psychological support services based on the needs of local PLWH are available, are delivered and are effectively coordinated.

Standard 8: evidence-based practice

All psychological assessment and interventions for people living with HIV (PLWH) should be based on the best available evidence.

8.1.1 Evidence-based assessment and interventions

All psychological assessment methods and psychological support interventions used across the four levels of stepped care should be selected and delivered according to the best available evidence of effectiveness.

8.1.2 HIV-appropriate assessment and intervention methods

Methods used for psychological and cognitive assessment and psychological support interventions for PLWH should have been developed, standardised and evaluated for use with HIV and/or other life-threatening long-term medical conditions.

Introduction

1 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.

Definition of 'psychological support'

For the purposes of this document, psychological support is defined as 'any form of support which is aimed at helping people living with HIV to enhance their mental health and their cognitive, emotional and behavioural wellbeing'.

Psychological support is provided at different levels of complexity by a wide range of professional groups, peers and informal providers, in clinical settings and in the community. Psychological support includes, but is not limited to, emotional support and the provision of a variety of talking therapies, cognitive rehabilitation and appropriate medication.

2 Who should use the standards?

The standards represent current best practice and are intended to apply to all services providing psychological support (as defined above) for adults living with HIV. These services may be provided by the statutory, voluntary or independent sectors and are mostly funded by the NHS or local authorities, although the standards are equally relevant for services funded by charities or paid for by service users themselves. The standards do not make recommendations for specific professional groups, but a list of practitioners who offer psychological support of different kinds can be found at Appendix C.

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 (PLWH) to help them define the minimum expected from services. It is designed to facilitate equitable access to psychological support of consistent and high quality, regardless of location or provider. In the context of decision making about the availability and configuration of local services, psychological support services for PLWH should be planned and adequately resourced in accordance with these standards.

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 PLWH are entitled to expect the same standards of care.

It is recognised that some services providing psychological support across the UK at the present moment are not meeting these standards. Where they do not, the needs of PLWH are not being adequately met and this will have negative implications for their mental and physical health outcomes. It is intended that the standards should act as a catalyst for improving the response to those needs.

3 Why is psychological support for people living with HIV important?

HIV and health inequality

The number of people living with HIV in the UK continues to rise, with an estimated 86,500 infected at the end of 2009[1]. Men who have sex with men (MSM) and black African heterosexuals are the groups with the highest prevalence. The proportion aged 50 or over is rising[1] while young people account for one in ten new diagnoses[2].

High prevalence of psychological problems

The prevalence of psychological and psychiatric problems among people living with HIV is substantially higher than in the general population[3,4,5]. People with HIV are about twice as likely to be diagnosed with depression as matched controls in the general population[6]. HIV tends to be concentrated in vulnerable and stigmatised populations who are already at greater risk of mental health problems than the general population[7] and HIV exacerbates this health inequality. Psychological difficulties can also result from receiving an HIV diagnosis and the challenges of living with HIV[8,9].

Impact on clinical management and worsening health outcomes

Whatever their causes, psychological problems complicate the care and clinical management of people with HIV by decreasing rates of adherence to antiretroviral therapy (ART), increasing loss to follow-up, reducing quality of life and leading to poorer health outcomes including clinical decline and mortality[10,11,12]. Such outcomes result in longer and more frequent hospital admissions and other costly interventions.

Psychological concerns in the era of antiretroviral therapy

HIV is now considered a long-term health condition in the UK, characterised by periods of good health punctuated with bouts of illness. But despite increased longevity and physical health HIV continues to be a difficult and stressful condition for many people. Recent research with PLWH[13] identified a complex array of concerns about quality of daily life and other personal, social and medical issues, with widespread reports of discrimination and social isolation. Such experiences, along with other psychosocial factors, have been shown to have a negative impact on health outcomes[14].

Higher prevalence of cognitive impairment and its outcomes

Cognitive impairment is also more common amongst PLWH than in the general population[15] and is an independent risk factor for earlier death[16]. It can contribute to poor adherence to medication[17], poorer functioning in daily life and loss of employment[18].

Increased risk of HIV transmission

Risky sexual behaviour is often associated with depression and substance misuse[19]. When this is combined with low adherence to ART which raises viral load, the risks of onward transmission of HIV are substantially increased.

4 Effectiveness of psychological support

Psychological support improves health outcomes

Over the last fifteen years, increasing attention has been given to the psychological welfare and management of people living with long-term health conditions. There is evidence that a range of psychological interventions

can make a considerable difference to the long-term health and wellbeing of someone living with HIV, including how well they manage their condition and adhere to treatment[20]. Psychological interventions leading to improved adjustment can improve neuroendocrine regulation and immune functioning[21].

Psychological support improves mental health and reduces risk of HIV transmission

Interventions, particularly cognitive behaviour and stress management interventions whether delivered through individualised or group methods, have been shown to enhance coping among PLWH[22]. Interventions directly targeting anxiety in PLWH have also been found to be effective, especially psychological interventions[23]. A range of approaches, in particular psychological interventions and especially those incorporating a cognitive behavioural component, have demonstrated effectiveness in reducing depression in PLWH[24].

By improving mental health outcomes as above, psychological support can reduce the risk of HIV transmission associated with psychological difficulties. More specifically, psychological interventions which address self-efficacy and behavioural skills training are an important part of improving adherence as well as enabling changes to HIV transmission risk behaviour[25].

Cognitive rehabilitation improves adherence and functioning

Cognitive rehabilitation can improve adherence to ART and day-to-day functioning in those with HIV-related cognitive impairment[26,27].

5 The economic case for psychological support

There are significant costs to the NHS and local authorities arising from the worsened health outcomes and more complex healthcare and social care needs of PLWH who have psychological and cognitive difficulties. In addition, ongoing transmission of HIV (which can be reduced through psychological support) increases the financial burden as the number of people living with HIV continues to grow. It is estimated that the prevention of one new HIV infection saves the public purse between £280,000 and £360,000 in direct lifetime healthcare costs[28].

Improving the mental health and psychological wellbeing of PLWH is a valuable outcome in itself. Interventions which achieve such improvements also play an important role in reducing negative health outcomes and the risk of HIV transmission. Critically, this means that investment in psychological support for PLWH is a way of preventing avoidable ill-health and avoidable costs through appropriate early intervention.

Thus despite competing claims on tight budgets, the provision of timely and appropriate psychological support to meet the needs of PLWH supports the objectives of the NHS Quality, Innovation, Productivity and Prevention (QIPP) programme.

Recent work to develop Payment by Results (PbR) tariffs for HIV outpatient care included analysis of HIV clinic activity. It found that the 2% of patients with complex psycho-social needs had the highest level of attendances per patient. However, it was acknowledged that the categorisation was subjective and that activity levels, which varied significantly between providers, did not necessarily reflect true levels of need[29]. Commissioning should therefore use local assessment of the extent of need, which will be greater at the lower levels of complexity (see stepped care model, page 22 and Standard 7), to ensure adequate levels of provision and access.

6 Why are standards needed?

To date, there have been no UK standards for the provision of psychological support for PLWH and the extent and quality of provision appears to vary. A multidisciplinary expert seminar convened in 2010 by the National AIDS Trust demonstrated a strong consensus that standards for HIV psychological support were needed to improve both the quality and the consistency of care across the country[30].

Psychological and cognitive difficulties are often underestimated by healthcare practitioners. As a result, it is possible that many PLWH are not offered access to the services they need[31,32,33]. If needs are underestimated or the health and economic benefits of psychological support are not recognised, there is a risk that commissioners may fail to invest in services providing psychological support, with a resulting negative impact on health outcomes and associated costs.

The standards therefore provide evidence-based recommendations to guide commissioning and service provision, using a stepped care model with relevance for all practitioners. This is done in order to ensure that appropriate psychological support is available to meet the diversity of needs of PLWH.

7 HIV-specialist psychological support

Frameworks developed for psychological support for the general population or for those with other long-term conditions may be relevant for PLWH. However, there are particular aspects of HIV and its care which mean that different assessment and intervention methods may be appropriate. Given these unique aspects of living with HIV, additional competencies are also needed by practitioners at all levels.

- Services providing psychological support for PLWH need to recognise the impact of the stigma associated with HIV and understand the experience of the population groups most affected by HIV in the UK (ie men who have sex with men and black Africans). People from black and minority ethnic (BME) communities are less likely to be offered or to take up, and more likely to drop out of, talking therapies[34,35,36,37,38], and there is reason for concern about the ability of mainstream psychology, counselling and psychotherapy providers to meet the needs of lesbian, gay, bisexual and transgender (LGBT) communities[39].

- It is important that services are able to provide appropriate, culturally sensitive and effective support in relation to sexual behaviour and reducing the risk of transmission. Practitioners without specific expertise in this area are often not comfortable or experienced in discussing issues of sex and sexuality, including the specifics of sexual practices, or issues of disclosure with sexual partners.

- Support for PLWH may involve support for other family members who may also have HIV and/or for carers, who in turn can play a valuable psychological support role.

- Practitioners need an understanding of the physical impact of HIV infection and HIV therapy, how this may affect psychological and cognitive functioning, and the implications of this for the use of assessment and intervention methods. Specifically, neuropsychological assessment in HIV is a specialist area for which the skills and materials are usually only available in HIV-specialist centres.

Although not currently available in all areas, there are pragmatic reasons why HIV-specialist provision for people who have psychological problems at levels 3 and 4 (see the stepped care model, page 22) can be beneficial where possible, rather than PLWH being seen in generic mental health services.

- Physical care and psychological support should, as far as possible, be combined into a single care package. A stepped care model also needs to have all levels of provision within the same pathway.

- Behavioural interventions to reduce the risk of transmission need to be an integral part of psychological support for PLWH and delivered by the same practitioners to ensure an integrated approach.

- PLWH are often treated for HIV outside their own catchment area, especially in the bigger centres. It is difficult for HIV treatment services to liaise effectively with mental health services in a different area, sometimes at significant distance, let alone develop effective pathways.

- Having HIV-specialist provision available may enable faster and smoother access to psychological support than referral to general psychological support services. Faster access reduces negative outcomes, such as non-adherence to ART, clinical complications and hospital admissions, and their associated costs.

8 Policy drivers for the development of standards

The standards are in tune with the direction of current government policy and guidance from leading professional bodies in the field.

Professional guidelines

Standards and guidelines for the management of HIV focus principally on medical aspects of care and treatment[40], although some mention specific aspects of psychological support such as post-test discussion[41] or sexual and reproductive health advice[42]. *Recommended standards for NHS HIV services* highlight the importance of meeting socio-cultural, psychological and neurocognitive needs, and of networking between service providers to ensure PLWH receive comprehensive and integrated care[43].

Government policy (England)

The NHS White Paper *Equity and excellence: Liberating the NHS* places emphasis on achieving healthcare outcomes by implementing quality standards[44]. These will inform the commissioning of all NHS care and form the basis for determining the effectiveness of service provision.

The cross-governmental mental health outcomes strategy, *No health without mental health* recognises the higher rates of mental health problems in people with long-term physical health conditions and the need to improve access to therapies[45]. This is reflected in *Talking Therapies: a four year plan of action* which outlines the roll-out and expansion of the Improving Access to Psychological Therapies (IAPT) programme and specifically refers to the need for psychological therapies to be available for PLWH[20]. It makes a commitment to providing continuous professional development training for healthcare workers involved in delivering psychological therapies to people with long-term conditions.

Government policy (Scotland)

The Scottish Government's *Sexual Health and Blood Borne Virus Framework 2011-2015* notes that "specialist clinical, psychological, social and peer support is critical in maintaining contact and support from the moment of initial diagnosis through to management of HIV as a long-term chronic condition" and calls for multi-agency working to provide high-quality HIV treatment and care and support[46].

Government policy (Wales)

The care pathways and service specification set out in the Welsh Assembly Government's *Providing for the*

needs of people with HIV/AIDS in Wales describe access to different types of psychological support, ranging from counselling and emotional support through to clinical psychological and psychiatric interventions[47].

Policy and guidance on prevention

Like long-term condition management, prevention is also an increasing government priority, as set out in the Public Health White Paper for England *Healthy Lives, Healthy People*[48]. There is a growing emphasis on psychological support for PLWH to help prevent HIV transmission. NICE public health guidance on prevention of STIs including HIV makes recommendations for managing partner notification[49]. The forthcoming *UK National Guideline on Safer Sex Advice* (in development) includes specific recommendations on the prevention of sexual transmission of HIV, including advice for those working with PLWH[50]. Health Improvement Scotland's *Standards for HIV Services* recommend the offer of a range of tailored, intensive behaviour change interventions, where required, by a dedicated team led by an individual with specialist training in this area, usually a clinical psychologist[51].

9 Contextual drivers for the development of the standards

There is a wide and variable range of psychological support services within and across the UK nations. Models of organisation vary, with some psychological support services located alongside medical services and others based in the community.

Psychology and psychiatry

Although in some areas psychology services are part of multi-disciplinary HIV teams, clinical and counselling psychologists may not always be part of the same organisational structure as their medical colleagues. Similarly, while HIV-specialist psychiatric care is provided within some larger HIV treatment centres or liaison psychiatry services, in many parts of the country psychiatric support for people with HIV is available only through general psychiatry where experience of treating HIV-related psychiatric problems may be minimal.

Other psychological support

The provision of many other kinds of psychological support is also variable in terms of availability, access and service models. Services such as counselling, psychotherapy, health trainers and peer support are often provided by voluntary sector organisations in community and/or hospital settings. The extent of the health adviser role varies between services and, while other members of clinical and social care teams usually provide some kind of supportive communication and can often identify psychological support needs, this may be more or less formally recognised.

Cognitive impairment

Interventions for cognitive impairment for PLWH are provided in acute hospital rehabilitation facilities and by community rehabilitation teams. They may be embedded within HIV-specialist services but in most parts of the country they are accessed through general rehabilitation or neuro-rehabilitation services. Assessment and interventions are provided by clinical psychologists and neuro-psychologists, neuro-psychiatrists, occupational therapists and speech and language therapists. There is a strong relationship between emotional, psychological and physical wellbeing and cognitive functioning. Therefore, services that improve emotional, psychological and physical wellbeing are recognised as also having a positive effect on cognitive health and function[52].

Service access and quality

Local HIV prevalence and the profile of population groups affected by HIV vary significantly around the country. Service models and locations also differ, but there should not be inequity in access or service

quality. It is particularly important at a time of financial constraint that the health and economic benefits of psychological support are recognised, that PLWH have access when needed to psychological assessment and support, and that the services provided are of high quality and based on the best available evidence.

10 Scope of the standards

The standards cover psychological support of all kinds for adults diagnosed with HIV, from the point at which they are diagnosed.

For the purposes of this document, psychological support is defined as 'any form of support which is aimed at helping people living with HIV to enhance their mental health and their cognitive, emotional and behavioural wellbeing'.

Psychological support is provided at different levels of complexity by a wide range of professional groups, peers and informal providers, in clinical settings and in the community. Psychological support includes, but is not limited to, emotional support and the provision of a variety of talking therapies, cognitive rehabilitation and appropriate medication.

What is outside the scope of these standards?

A range of factors influence psychological outcomes in PLWH. While psychological support plays an important role, there are other significant influences including social and economic circumstances, life experiences (eg immigration), community attitudes and stigma, medical care and medication, including ART. The standards recognise the impact of all these factors but their scope does not extend to recommending how to address them. The remit of this document is to make recommendations specifically for psychological support.

The following topics are important but they are outside the scope of the standards.

- HIV testing and pre-test discussion, except insofar as these are relevant for psychological support following a positive test.
- Guidance or recommendations about specific treatments, such as pharmacotherapy or cognitive behavioural therapy (CBT), or specific screening tools.
- Psychological support for children. However, these standards are relevant for adults living with HIV who are also parents and may use family services, as well as for young people who have just made the transition from children's to adult services - it is proposed that parallel standards should be developed for children and adolescents.
- Psychological support specifically for carers and other affected individuals, except insofar as the psychological support for individuals living with HIV encompasses this.
- Particular service models or types of service which should provide the care described, because service configurations vary according to local circumstances - the standards describe the care that people with HIV should receive, regardless of the setting or who provides it.
- The full detail of competencies required by individuals providing psychological support at all levels. However, the standards refer to existing competency frameworks and professional qualifications relevant for the provision of the care they describe and highlight some key competencies. Similarly, where possible, the standards draw on and refer to relevant existing documents such as broader service standards, clinical guidelines and best practice guidance produced by professional, governmental or regulatory bodies.

- How to meet the psychological support needs specific to different population groups and the diversity within them. However, services developed in line with the standards need to take account of the differing needs of those groups at local level.

The focus of these standards is the psychological support PLWH should receive. While they are relevant for the providers of generic mental health services, they do not set out to address the many ways in which any mental health services should respond to HIV – a task which merits a separate project.

11 What is in each standard (structure/format)?

The standards cover the key components of psychological support for adults living with HIV. They complement and reference existing guidance for other aspects of HIV treatment and care and generic guidance for relevant disciplines such as counselling, psychotherapy, psychology and psychiatry.

Underpinning all of the standards is the stepped care model (see page 22) which outlines the comprehensive provision of psychological support, making the most of resources at all levels of expertise.

There are eight standards, each containing:

- a standard statement followed by a number of recommendations
- a supporting rationale, which explains why the recommendations are made
- implications for commissioning and locally-based planning (relevant in different ways in different parts of the UK according to funding systems)
- auditable outcomes offering a way to measure whether the standards are being met
- references and a list of further relevant supporting documents and guidance. Where there are no references, the recommendations represent best practice as identified by the project Working Party.

12 Audit and evaluation

The purpose of these standards is to ensure that all PLWH have access to the most appropriate and effective psychological support. As with any standards, they will only have an impact on quality of care if they are implemented. Evaluation and audit can be used to measure whether the standards are being implemented by services providing psychological support for PLWH. This exercise may be undertaken on an individual service basis or coordinated across the local health economy or local HIV service network.

Auditing and evaluating services involves a systematic process of looking at current practice and comparing it to standards of best practice. It is a proven method of quality improvement and it can highlight problems, identify gaps and assist in developing solutions. Auditing of indicators which measure practice can be supplemented by monitoring of outcomes which demonstrate the impact of the standards.

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.

The Auditable outcomes section (page 65) sets out suggested indicators to measure practice against these standards and their impact on outcomes.

13 Language and terminology

The language used in this document reflects agreement among the project Working Party and feedback from consultation. The glossary at Appendix A provides an explanation of some of the terms used.

Except in specific contexts where it is necessary, the term 'patient' is rejected in favour of 'person living with HIV'. For speed of reading, and in line with much other literature in the HIV community, this is abbreviated to PLWH.

The term 'practitioner' is used in the standards to describe anyone providing psychological support. This has been chosen as an inclusive term which encompasses a wide range of health and social care professionals as well as others such as community sector volunteers and peer support workers.

14 Who developed the standards and how?

Following the recommendations of a seminar convened in July 2010 by the National AIDS Trust to examine the psychological support needs of people with HIV[30], the standards were produced in partnership by:

- the Faculty for HIV & Sexual Health (FacHIV&SH) of the Division of Clinical Psychology of the British Psychological Society
- the British HIV Association (BHIVA)
- the Medical Foundation for AIDS & Sexual Health (MedFASH).

A multidisciplinary Working Party chaired by the FacHIV&SH brought together representatives of key professional bodies and other experts, including members of the following national organisations:

- British Association for Counselling and Psychotherapy (BACP)
- British Association for Sexual Health and HIV (BASHH)
- British HIV Association (BHIVA)
- British Psychological Society, Faculty for HIV & Sexual Health of the Division of Clinical Psychology
- Medical Foundation for AIDS & Sexual Health (MedFASH)
- National AIDS Trust (NAT)
- National HIV Nurses Association (NHIVNA)
- Royal College of General Practitioners (RCGP)
- Royal College of Nursing (RCN)
- Royal College of Psychiatrists (RCPsych), Faculty of Liaison Psychiatry
- Society of Sexual Health Advisers (SSHA).

In addition, the Working Party included:

- a service user representative
- three voluntary sector providers of psychological support services (Terrence Higgins Trust [THT], George House Trust [GHT] and Mildmay UK)
- an NHS commissioner
- a local authority HIV-specialist social worker.

Further input was gained from a meeting with voluntary sector community providers about the types of service they offer, their approach to ensuring quality of care, and their concerns and suggestions in relation to the development of standards.

Working Party members developed drafts of the standards, advised on technical content and editing, and provided guidance on the management of the project, external consultation and broader project issues,

including formal endorsement of the standards.

The FacHIV&SH and BHIVA provided clinical leadership for the project and facilitated consultation on the draft standards. MedFASH managed the project, contributed to drafting and undertook the editing and publishing of the document.

Consultation on the standards took place in April and May 2011.

Appendices E, F and G provide lists of Working Party members, voluntary sector community provider meeting participants and organisations responding to consultation respectively.

15 Reviewing and updating the standards

To ensure their content remains up-to-date and relevant, it is intended to review and update the standards after two years.

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The stepped care model

People living with HIV (PLWH) can often assess their own emotional support needs and meet them by themselves. This might involve choosing support from family, friends or self-help and support groups. They may also develop personal self-management strategies on their own and self-refer to services they know how to access.

However, PLWH may require some form of psychological support to help them with their needs. The following model (Figure 1) outlines comprehensive stepped care for psychological support provision which makes the most of resources at all levels of expertise in order to:

- improve health outcomes and experiences of PLWH
- improve quality of life of PLWH
- prevent the development or exacerbation of more severe psychological and psychiatric problems
- cost-effectively utilise limited resources
- help in the planning and provision of psychological support services based on need
- promote positive wellbeing.

The model describes four essential levels of psychological support provision for PLWH based on levels of complexity of need, against which is mapped increasing practitioner training, specialism in psychological and psychiatric problems and competency. It presents these in relation to the types of assessment and interventions required of providers. It may not always be possible to make clear distinctions between the boundaries of expertise of various practitioners and it is likely that some overlap may occur. This is a reactive model which should be used alongside proactive prevention and outreach models to maximise PLWH engagement and wellbeing. It is beyond the scope of this model to prescribe assessment tools although a range is described in the references and supporting documents for Standard 5.

It is also beyond the scope of this model to list potential providers within different settings as it focuses rather on competency of providers relating to need.

Care pathways based on this model can be linked to practitioner competencies (see Standard 7) in order to provide holistic care and to avoid duplication of roles, inequalities in provision of psychological support between localities, or a lack of recognition of psychological and psychiatric problems, and to ensure that practitioners operate within their levels of competence. Standards 2 and 7 outline how the model can be used to provide comprehensive and coordinated psychological support pathways.

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

LEVEL	ASSESSMENT	INTERVENTIONS
1 **Information and support**	Understanding psychological needs of people living with HIV Understanding of risk of harm to self and others Recognising overt psychological distress	Effective provision of relevant information in accessible formats Supported self-help Signposting and referring to appropriate providers Response to overt distress Supportive communication and general psychological support Signposting self-management strategies eg books and computerised resources, newly diagnosed courses Peer support
2 **Enhanced support**	Screening for psychological distress Screening for cognitive difficulties Assessment of risk of harm to self and others	Discussions aimed at acceptance and adaptation to living with HIV Signposting and referral to more appropriate services and peer support Education sessions around the nature of psychological and psychiatric problems and how to cope with them Brief interventions aimed at behavioural change eg sexual risk behaviour and substance misuse
3 **Counselling and psychological therapies (HIV-specialist)**	Assessment and formulation of psychological problems Identification of psychiatric problems Screening for cognitive impairment Assessment of risk of harm to self and others	Counselling and psychological interventions based on explicit theoretical frameworks for specific psychological difficulties such as: • moderate or severe anxiety • substance misuse • moderate or severe depression • psychosexual or relationship problems • sexual trauma/ PTSD Interventions for cognitive impairment Psychological interventions based on explicit theoretical frameworks to develop and enhance positive psychological processes such as adaptive coping strategies which increase resilience
4 **Specialist psychological and mental health intervention (general or other specialist)**	Psychiatric diagnosis Neuropsychological assessment Assessment and formulation of complex psychological problems Assessment for cognitive impairment Assessment of risk of harm to self and others	Specialist psychological and psychiatric interventions for severe and complex psychological problems, cognitive impairment, PTSD or co-morbid psychiatric problems such as: • psychosis • severe depression • mania • eating disorders • personality disorder • cognitive impairment and for specific situations such as: • complex adolescent and family issues Cognitive rehabilitation

The psychological assessment and psychological support interventions provided at each level of the stepped care model can be summarised as follows.

Level 1

Level 1 psychological support is provided by all practitioners directly responsible for the care of PLWH in statutory and non-statutory services. Level 1 psychological support focuses on general supportive emotional care, supported self-help, signposting and the identification of more serious problems for onward referral. All PLWH should have access to this level of care.

Assessment

All practitioners at this level should:

- understand psychological distress and risks
- avoid causing psychological harm to patients and those affected by HIV
- know when they have reached the boundary of their competence and refer on when this is reached
- have an understanding of referral pathways and referral criteria for more specialist services (see Standard 7)
- understand issues relating to confidentiality and disclosure of HIV status
- understand cultural issues pertaining to HIV, health beliefs, sexuality and stigma.

Interventions

Interventions at this level include:

- general psychological support based on skilled communication
- provision of information on the wider range of resources and services available
- establishing and maintaining supportive therapeutic relationships
- treating PLWH with compassion, dignity and respect
- understanding HIV as a stigmatising condition and respecting confidentiality
- talking about sexual matters and clearly but empathically breaking bad news
- guided and supported self-help.

Level 2

Level 2 psychological support is provided by practitioners who have additional expertise in providing psychological support through training and experience. This will include brief interventions that are standardised in manuals such as motivational interviewing and post-test discussion.

Assessment

Practitioners operating at this level should provide formal screening for psychological distress and cognitive difficulties at key points in the life of PLWH, and assess risk of harm to self and others, for example:

- at time of HIV diagnosis
- at initial onset of physical symptoms
- when there are negative changes in blood counts or other changes in physical health status
- when starting or switching HIV medication
- at times of non-adherence
- at the development of medication side-effects

- at times of treatment failure
- after change of treatment centre
- after a period of non-attendance and loss of contact with treatment centre
- at the development of psychosocial problems such as immigration, relationship difficulties or bereavement
- when experiencing family problems including those arising from children's HIV status
- when experiencing stigma, violence or abuse
- at times of co-infection, such as with hepatitis B/C or tuberculosis (TB).

Practitioners should be able to screen for psychological distress and cognitive difficulties and to use counselling techniques to elicit worries and feelings that a PLWH may have in an empathic, non-judgemental way. If significant psychological distress is identified they should also be equipped to contain this and to refer on to specialist psychological support. They should also be able to assess PLWH's competence to consent to referral and treatment (see Standard 6 on competencies required).

Interventions

Level 2 psychological support interventions can include discussions around adaptation to having HIV, newly diagnosed courses, life coaching, problem solving, motivational interviewing around HIV prevention, adaptation to illness and signposting. Level 2 psychological support practitioners should have competencies (see Standard 6) to provide structured psychological interventions, such as:

- pre- and post-test discussion
- chronic disease management
- adherence support
- sexual risk reduction
- antenatal and post-natal support
- peer support groups
- support around adaptation to living with HIV
- education around coping with and understanding mental health problems
- substance misuse support.

These practitioners should work within agreed referral and communication pathways and to specific referral criteria. They should also practice within their levels of competence and know when to refer onwards.

Level 3

Level 3 psychological support is provided by qualified, professionally registered practitioners in counselling and psychological therapies who receive appropriate supervision.

Assessment

Assessment at this level should be carried out by practitioners with qualifications and professional registration in psychological therapies and interventions, or professionally registered and supervised practitioners from other disciplines who have completed accredited training to achieve the required competency in psychological therapies and interventions (see Standard 6 on competencies required). Practitioners should formulate psychological problems, assess risk of harm to self and others, confirm competence of PLWH to consent to referral and treatment, and differentiate between moderate and severe levels of psychological need that may require referral to psychological or mental health specialists. Screening for cognitive impairment will be carried out by appropriately trained and accredited practitioners at this level.

Interventions

Level 3 psychological support interventions are based on explicit theoretical frameworks with proven effectiveness for specific psychological issues that may be more complex such as anxiety, depression, substance misuse, psychosexual or relationship problems, cognitive impairment or sexual trauma. This can also include psychological interventions focussed on developing and enhancing adaptive coping strategies that increase positive psychological outcomes such as resilience. Medication management of conditions such as anxiety and depression at this level may be undertaken. Interventions for cognitive impairment may also be carried out by appropriate practitioners.

Level 4

Level 4 psychological support is provided by psychological and mental health specialists who have clear pathways developed from HIV services. To enable PLWH to receive general (non-HIV-related) psychological and psychiatric provision when needed, referral from liaison psychiatry or HIV-specialist counsellors and psychological therapists is preferred. However, where these roles are absent, more direct pathways to level 4 will need to be developed from services at levels 1 and 2.

Assessment

Assessment at this level should be carried out by mental health specialists. These professionals should provide assessment of severe psychological problems in the context of physical ill-health, or psychiatric problems such as severe depression, substance misuse, personality disorders, psychosis, or mania. In order to ensure a holistic assessment of needs, even where the psychological or psychiatric problems predominate, they should have competency in assessment of co-existing psychiatric and physical health conditions. Assessments could involve psychiatric diagnosis and risk assessment and lead to the psychological formulation of complex problems from a variety of psychological theoretical frameworks. Cognitive assessment will be carried out by appropriately trained and accredited practitioners at this level and may include neuropsychological testing for HIV-associated cognitive impairment.

Interventions

Level 4 psychological support requires specialist evidence-based psychological and psychiatric interventions to manage severe or complex HIV-related psychological problems or severe mental health problems, such as psychosis, mania, personality disorder, severe depression and delirium. (Delirium can be particularly difficult to diagnose for PLWH particularly when they have other existing mental health problems.) Severe mental health problems are usually managed in multidisciplinary mental health teams. Psychiatric treatment could also relate to complex prescribing issues including attention to drug interactions or contraindications to specific medication regimens in people with other health problems. This level of intervention may necessitate provision of emergency psychiatric services in addition to outpatient, inpatient and community services. Interventions for cognitive impairment at this level would be delivered by a multidisciplinary cognitive rehabilitation team.

Figure 2: filter model of provision of psychological support for people with HIV

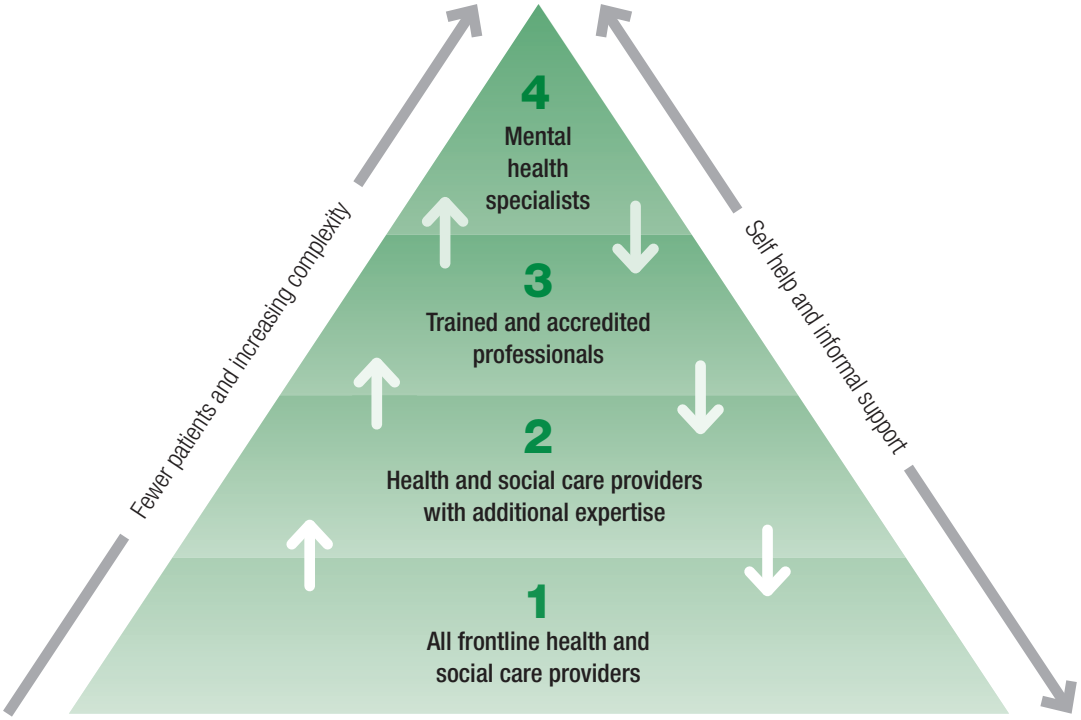

Figure 2 demonstrates the filter model of psychological support and the variety and expertise of practitioners associated with each level of psychological support. Level 1 indicates that all frontline care providers for PLWH provide for low level psychological needs. As the degree or complexity of need increases, psychological support is provided by practitioners of increasing expertise and specialisation. The highest level of psychological support, level 4, is provided by practitioners with specialist psychological or psychiatric expertise. Supported self-help and informal support is encouraged at all levels of psychological support. The diagram, with a wide base, decreasing to the apex, indicates the decreasing numbers of practitioners required at each increasing level of support in line with the decreasing number of PLWH requiring psychological support at each level. Throughout their journey with HIV, PLWH may move both up and down the model as their needs change. Clarity can be achieved by using the model as a template for developing pathways in order to facilitate referral and discharge between the levels.

Further supporting documents and guidance

This model of stepped care was inspired by models in the following documents:

Gutmann M & Fullem A (2009) *Mental Health and HIV/AIDS.* Arlington, VA: USAID/AIDSTAR-One
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Standards for psychological support for adults living with HIV

STANDARD 1

Promotion of mental health and psychological wellbeing

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

1.1 Recommendations

1.1.1 Psychological wellbeing on the agenda

PLWH should be given the opportunity to discuss their psychological wellbeing with the professionals providing their health and social care.

1.1.2 HIV-sensitive care

PLWH should receive confidential, non-stigmatising care that is informed by an understanding of the unique HIV-related factors affecting psychological wellbeing.

1.1.3 Information to promote psychological wellbeing

During their contact with health and social care services, PLWH should be provided with information and resources promoting their psychological wellbeing, such as leaflets, posters and websites, as well as access to patient/service user representatives and peer support.

1.2 Rationale

1.2.1 Psychological wellbeing on the agenda

PLWH report not being asked questions relating to their psychological wellbeing by some clinicians[1]. This is despite a large body of evidence showing a high prevalence of psychological difficulties associated with HIV infection. Difficulties include anxiety, depression, post-traumatic stress disorder, coping difficulties, sexual problems, suicide and neurocognitive problems[2,3,4,5,6,7,8,9,10].

1.2.2 HIV-sensitive care

PLWH report experiencing HIV-related stigma from health and social care professionals, especially those not specialising in HIV[11,12].

PLWH face challenges similar to those of people living with other long-term conditions. Depression affects approximately one in five people living with a chronic health condition, two to three times the rate of those without[13]. Some symptoms (eg fatigue) are common in people with either mental or physical ill-health.

In addition, PLWH may face social issues and challenges specific to HIV, including stigma and discrimination[14] which can exacerbate fears relating to disclosure of HIV-positive status[15,16]. They also need to deal with the potential for onward transmission of infection and the risk of criminal prosecution for HIV transmission[17]. Assuring the confidentiality of services caring for PLWH is of high importance, as is publicising this confidentiality to service users - and potential users - in order to encourage service uptake and open communication.

PLWH may also have conditions which are a direct result of HIV infection, such as HIV-associated cognitive impairment[18].

The promotion of psychological wellbeing through engagement in care is most effective when it is built on social networks already in place and uses a combination of methods focusing on individuals, families and communities. Support for self-management strategies can benefit from involvement of carers. When people have a limited personal support network, interventions such as peer support (see 3.2.2) can be helpful in addressing problems of isolation.

1.2.3 Information to promote psychological wellbeing

PLWH may not necessarily wish to talk to their clinicians about their psychological wellbeing. The provision of written, as well as verbal, information and the promotion of other resources such as websites during their clinic visit might either facilitate such a discussion, or allow signposting to services they feel able to access for psychological support. Contact with patient representatives and/or peer support provides a different way to convey information and may also facilitate access to further psychological support. Account should be taken of cultural, language and literacy needs, to ensure all PLWH have equitable access to information.

1.3 Implications for commissioning and planning

1.3.1 Services providing healthcare, social care or any other support to PLWH should be explicitly required to promote their psychological wellbeing and that of other individuals affected. This should include interventions that enhance social inclusion and combat stigma and discrimination.

1.3.2 Services providing healthcare, social care or any other support to PLWH should be required to ensure their workforce understands the HIV-specific factors which can affect psychological wellbeing and knows how to apply this understanding in its work.

1.3.3 The commissioning or funding of services for PLWH should include provision for the availability of information resources, and space for their display (eg leaflets in clinics, information on websites, posters in waiting rooms etc). Peer support and/or expert patient programmes should also be commissioned.

1.4 Auditable indicators

1.4.1 Proportion of service users who report that:

a) their service providers give them sufficient opportunity to discuss their pscyhological wellbeing
b) their service providers understand the experience of living with HIV
c) they have experienced stigma from healthcare practitioners in the last year
d) they receive information about HIV and their care which makes them feel better.

(Measurable through surveys of service users.)

1.4.2 Evidence that accurate, evidence-based information is provided within services for PLWH, including information in languages and formats to meet local needs and information materials from accredited providers. (Measurable through observation and surveys of service users.)

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STANDARD 2

Comprehensive psychological support services

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

2.1 Recommendations

2.1.1 Assessment for psychological support

All PLWH should be assessed for the appropriate level of psychological support to meet their needs.

2.1.2 Stepped care model

The stepped care model (see page 22) should be used to plan and enable access to the psychological support services needed by each individual at levels 1, 2, 3 or 4 (see Introduction and Standard 7).

2.1.3 Access to interventions

All PLWH should be provided with level 1 psychological support that includes information, signposting and supportive communication. They should also be provided, according to agreed referral criteria, with subsequent levels of more complex intervention when indicated through psychological and cognitive screening and assessment.

2.1.4 Timely access

Access to interventions should be timely, according to identified need. Where screening or clinical observation identifies a serious and immediate risk of harm to self or others, PLWH should be referred immediately to emergency mental health services (level 4). A pathway needs to be locally defined for access to these services. PLWH referred less urgently for specialist psychological support (level 3) should be seen within a maximum of three months.

2.2 Rationale

2.2.1 Assessment for psychological support

PLWH and their families are likely to benefit from some form of psychological support whether they experience mild and transient emotional symptoms, or more severe problems such as depression, anxiety, trauma or suicidal ideation[1,2,3]. Problems may recur, change in intensity and lead on to other problems such as anxiety or depression, leading in turn to relationship breakdown, isolation and suicidal behaviours[4], and they may also impede treatment for HIV-related illness[5].

The appropriate psychological support intervention will depend on the nature and severity of the person's problems, protective factors such as social support and resources and their individual preferences.

Assessment is therefore required to identify the appropriate intervention (or interventions) for each individual.

All PLWH should have access to assessment for psychological support whether referred by practitioners or through self-referral. Referral for assessment may follow a positive screen or identification of psychological or cognitive difficulties by practitioners.

2.2.2 Stepped care model

The stepped care model described on page 22 provides a framework for comprehensive assessment and provision of psychological support to meet the full range of needs of PLWH. While the particular services available locally may determine how such support is provided and by whom, all aspects of assessment and support provision described in the model should be available regardless of geographical location.

2.2.3 Access to interventions

Some practitioners who identify psychological distress may not know how to deal with emotional issues or where to turn for advice or support for distressed PLWH[6,7]. Yet practitioners offering frontline care can give much general psychological support to PLWH, their carers and those directly affected by the presence of HIV in their relationships. They can play a key role in psychological screening, signposting and distress reduction as well as behavioural prevention of HIV transmission and other health risks. All PLWH should have access to this level of support (level 1 in the stepped care model).

Some practitioners may also have particular skills in counselling which give them the competence to manage mild or transient psychological problems, such as adaptation and acute distress following an HIV diagnosis, or risky sexual behaviour. This type of psychological support may be provided in specialist HIV treatment centres, acute hospital settings, social care and community-based services, within or outside the district of the HIV service.

Specialist services for more complex and long-term psychological problems include clinical or counselling psychology, liaison psychiatry and psychotherapy. These may be available as an integrated part of the HIV service or may be part of local clinical health psychology services, generic mental health services, primary care, or the Improving Access to Psychological Therapies (IAPT) programme.

Interventions for cognitive impairment in PLWH are provided in acute hospital rehabilitation facilities and by community rehabilitation teams. They may be embedded within HIV-specialist services but in most parts of the country are accessed through general rehabilitation or neuro-rehabilitation services.

2.2.4 Timely access

In order to support PLWH in managing their condition and adhering to ART, access to interventions at all levels should be timely[5,8,9]. Waiting times and delays may cause further psychological difficulties and associated health problems, including non-adherence to ART. Therefore, PLWH should not experience delays in referral to services at levels 2, 3 and 4 when needed.

If the problem is urgent or with potential health risks, such as suicidal intent, immediate referral for further assessment with a mental health practitioner (level 4) and appropriate treatment should occur[10]. Suicide, attempted suicide and suicidal thoughts are all elevated in PLWH[11]. Prompt referral minimises the risk of

death in people who are actively suicidal as well as other risks associated with delays such as the risk of onward transmission of HIV.

Standards for the National Audit of Psychological Therapies[12], applicable to a wide range of services in the voluntary and statutory sectors, in primary and secondary care, within and outside the Improving Access to Psychological Therapies (IAPT) programme, are based on the aim that people referred to psychological therapies for depression and anxiety should be assessed and treated promptly. They state that the wait from the time of receipt of initial referral for psychological therapy to the time of assessment should not be longer than 13 weeks, and that a person who is assessed as requiring psychological therapy should not wait longer than 18 weeks from the time at which the initial referral is received to the time that treatment starts.

2.3 Implications for commissioning and planning

2.3.1 Commissioners, with providers, will need to gain an understanding of the nature and extent of psychological support needs of PLWH in their area and ensure appropriate services are available at adequate levels to meet the comprehensive range of psychological support needs identified (see Standard 7).

2.3.2 Commissioners should ensure that clear and defined pathways exist between services at different levels according to the stepped care model (see page 22).

2.3.3 Commissioning should consider the professional support and development arrangements for practitioners who are providing psychological support to PLWH sporadically.

2.3.4 In areas of lower HIV prevalence, HIV commissioners should link up with commissioners of related services, such as mental health and long-term condition management, to ensure the provision of comprehensive psychological support services. They should also work with local clinical or service networks where these exist. Such commissioning may be across a wider geographical footprint than in areas where HIV prevalence is higher.

2.4 Auditable indicators

2.4.1 When psychological support needs have been identified, the proportion of PLWH who have been referred on to appropriate psychological support.
(Measurable through occasional fixed-period audit of service user records in HIV treatment centres and community support organisations.)

2.4.2 Proportion of PLWH, in whom a serious and immediate risk of harm to self or others has been identified through screening or clinical observation, who are referred to emergency mental health services on the same day.
(Measurable through audit of service user records.)

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STANDARD 3

Engagement of people living with HIV

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

3.1 Recommendations

3.1.1 Engagement in service planning and development

PLWH should be consulted about the psychological support services they might wish to attend as well as the one(s) they do attend.

PLWH should be consulted and actively involved in the design, redesign and development of psychological support services.

Inclusive frameworks to engage PLWH, reflecting their diversity, should be developed across all services providing psychological support.

3.1.2 Engagement in service delivery

As part of psychological support service delivery, PLWH should play a role in the provision and dissemination of information about HIV and HIV services to other PLWH, as well as providing peer support, advice, advocacy and means of engagement.

3.1.3 Engagement in service evaluation

PLWH should be provided with opportunities for feedback on psychological support services as part of service evaluation, to inform service management and local policy.

The development, collection and reporting of outcome measures for psychological support services should include involvement of PLWH to ensure that these capture both clinical outcomes and user experiences.

3.1.4 Support for engagement of PLWH

PLWH who are involved with service user activities should be provided with opportunities to update and develop their knowledge and skills in order to maintain effective involvement with professional services and to ensure a consistent approach to psychological support.

3.2 Rationale

3.2.1 Engagement in service planning and development

PLWH play a central role in the response to the HIV epidemic. As those most affected, they will have a uniquely valuable insight into how services, programmes and policies should be designed for them, including psychological support services.

There is evidence at local, national, and international levels that PLWH involvement is essential to programme effectiveness[1,2,3,4,5].

Involving PLWH has also been endorsed in the internationally adopted GIPA principle. UNAIDS defines GIPA (Greater Involvement of People Living with HIV) as a principle that:

aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives[6].

The 2007 *Standards for HIV Clinical Care* require clinical care to be provided in partnership between clinicians, NHS organisations, patients and the wider public, stating that this entails patient and public involvement in planning and helping to design services[7]. Service user forums, networks and representatives are examples of how such engagement can be facilitated.

Section 242 of the National Health Service Act 2006 - Involvement and Consultation places a legal duty on NHS trusts, primary care trusts and strategic health authorities to make arrangements to involve and consult patients and the public in service planning and operation, and in the development of proposals for changes. All NHS services are now required to use patient and public engagement (PPE) approaches because they increase quality, ensure accountability, and are cost-effective[8,9]. The commitment to patient involvement is reiterated in current government policy for the NHS[10].

3.2.2 Engagement in service delivery

The involvement of service users in the development and delivery of HIV services has provided a model for user engagement in many other areas of healthcare. There are numerous benefits of engaging PLWH in all aspects of service delivery, including increasing effectiveness and quality. It is recognised that the engagement of PLWH in delivering services can play an important role in enhancing their self-efficacy as well as enabling outreach to groups that might otherwise be hard to reach[2].

Peer support services represent a key aspect of PLWH engagement. *Standards for HIV Clinical Care* recognise that peer support forms an integral part of good HIV care and recommend that clinical service providers actively foster access to peer support[7]. Peer support (provided by PLWH for PLWH) can take many forms including emotional support, advice, advocacy, information, workshops, forums and courses.

3.2.3 Engagement in service evaluation

Service user experience of treatment and care is a major indicator of service quality. This may be captured through a variety of mechanisms including satisfaction surveys, qualitative interviews, focus groups and rating scales that measure states of health and illness from the perspective of the service user.

Patient-reported outcome measures (PROMs) provide a means of gaining an insight into the way patients perceive their health and the impact that treatments or adjustments to lifestyle have on their quality of life. Health status information collected from patients by way of PROMs questionnaires before and after an intervention provides an indication of the outcomes or quality of care. Currently, providers of NHS-funded care are required to report on PROMs for certain elective healthcare interventions[11], and work to develop new PROMs for long-term conditions has been initiated[12], but this does not include HIV and there are as yet no nationally developed PROMs for HIV treatment and care.

However, within a service or across a local network, PROMs or patient-reported experience measures (PREMs) might be locally developed and agreed with service users and then used to measure service quality. Measures should examine, for example, access, communication, interaction with professionals, coordination, care and respect, privacy and dignity, information about mental health and wellbeing, involvement in decisions and overall experience (see also Standard 8).

3.2.4 Support for engagement of PLWH

PLWH may wish to participate in planning, delivering and providing feedback on psychological support services but lack the confidence or skills to do this effectively. The process of engagement should therefore include the provision of information, training and support on an ongoing basis to empower and enable PLWH to develop the relevant skills.

3.3 Implications for commissioning and planning

3.3.1 Commissioners and providers should engage with PLWH organisations, service user groups or representatives in the development of their local vision for psychological support as part of strategies for local HIV treatment, care and support. Engagement of PLWH should appear clearly in strategy implementation plans.

3.3.2 Specifications for services providing psychological support for PLWH should include arrangements for the involvement of PLWH in the planning, monitoring and evaluation of these services. Consideration should be given to ways of measuring self-perceived health outcomes as well as the experience of using services.

3.3.3 Commissioners should require providers to involve PLWH appropriately in the delivery of psychological support and to provide training, supervision and support to enable their participation to meet consistent quality standards.

3.3.4 The resourcing of local commissioning and provision of services for PLWH should include allocations to support the engagement of PLWH in planning, delivering and evaluating services.

3.4 Auditable indicators

3.4.1 Evidence from providers of HIV-specialist psychological support that they have:

a) developed a plan for engaging PLWH
b) implemented the plan
c) taken action in response to PLWH input.

3.4.2 Inclusion of patient-reported outcome measures (PROMs) and/or patient-reported experience measures (PREMs) in audits and evaluations of psychological support provision.

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STANDARD 4

Support at the time of diagnosis

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

4.1 Recommendations

4.1.1 Support and information at the time of diagnosis

At the time of their HIV diagnosis, all PLWH should be offered one-to-one emotional support by the practitioner giving them the test result. If after the initial post-test discussion more in-depth counselling or other support is urgently needed, rapid referral to an appropriate provider should be offered if this is beyond the competence or capacity of the testing provider.

Immediately relevant information about HIV infection and its implications should be given verbally at the time of diagnosis and backed up by provision of, and signposting to, written information as appropriate.

Regardless of where testing takes place, all practitioners providing test results and emotional support at the time of diagnosis should have the competence to do this, with access to relevant training and professional support.

4.1.2 Referral for psychological support following diagnosis

Clear local policies and pathways for post-diagnostic support and referral should be in place and apply to all settings offering HIV testing. All newly diagnosed PLWH should be offered psychological support from practitioners with expertise in HIV at the earliest possible opportunity, preferably within 48 hours and certainly within two weeks of receiving the test result.

4.2 Rationale

4.2.1 Support and information at the time of diagnosis

People can experience very strong feelings, such as shock or anxiety, when they receive bad news. This can make it difficult for many people receiving a positive HIV test result to process information immediately following their diagnosis, especially if the news is unexpected[1]. Provision of accurate written information, such as in leaflets or online materials, can reinforce messages that may be hard to retain at this stage.

People may develop an acute stress reaction following an HIV diagnosis. Receiving a positive HIV test result without adequate emotional support may lead to a failure of PLWH to engage with services and becoming

lost to follow-up. Healthcare professionals and other practitioners offering HIV testing should follow UK HIV testing guidelines and obtain informed verbal consent before testing. They should also be prepared for the possibility of giving a positive result and ensure that they have the competence to do this, and to manage the conversation which follows. This may include helping the newly diagnosed person to plan the next 24 to 48 hours and the offer of a follow-up appointment within that period if necessary.

All practitioners giving HIV test results should be fully competent in enhanced communication skills and giving bad news. For many, such as those in general practice or hospital settings, giving bad news will already be part of their professional remit. Access to appropriate professional support and guidance from a specialist in providing psychological support should also be available to practitioners when needed.

As HIV testing is increasingly undertaken in non-traditional or non-HIV-specialist settings, whether in the community or hospitals, the ability of testing providers to offer more in-depth support will vary. If further immediate post-test support is needed at the time of diagnosis, beyond that which the service giving the test result has the competence or capacity to provide, this should be arranged with a sexual health, HIV support or other appropriate service using links which should already be in place. An after-hours support contact number should also be offered.

4.2.2 Referral for psychological support following diagnosis

Prior to giving a positive test result, practitioners should have clarified knowledge of local HIV-specialist services and established a clear pathway of onward referral for assessment and care, including rapid access for those who need urgent psychological support.

The *UK National Guidelines for HIV Testing 2008* recommend that any individual testing HIV-positive for the first time is seen by a specialist (HIV clinician, specialist nurse or sexual health adviser or voluntary sector counsellor) at the earliest possible opportunity, preferably within 48 hours and certainly within two weeks of receiving the result[2].

According to current *Standards for HIV Clinical Care*, all patients should be assessed by a doctor who provides HIV care within two weeks of a positive HIV test result, irrespective of the place of testing, unless the patient chooses to defer this. Arrangements for more rapid access must be in place for those with symptoms and/or particular needs or high levels of anxiety[3].

The testing guidelines state that the HIV/Genitourinary Medicine (GUM) specialist team will perform more detailed post-test discussion, including assessment of disease stage, consideration of treatment, and partner notification. Such discussion is also likely to cover how to prevent onward HIV transmission and ongoing support for the PLWH, and partner or family where appropriate.

As part of these recommended arrangements and within the same timeframes, early access to psychological support at levels 1 and 2 from practitioners with expertise in HIV (see stepped care model, page 22) should be available to PLWH following diagnosis, whether within the HIV-specialist centre or other setting. Pathways should also be in place for timely referral post-diagnosis for psychological support at levels 3 or 4 as needed (see also Standards 5 and 7).

4.3 Implications for commissioning and planning

4.3.1 Commissioners and service planners should ensure that services offering HIV testing provide information and emotional support at the time of diagnosis, and offer referral within the timescales set out in these standards for all people diagnosed with HIV.

4.3.2 Commissioners and service planners should ensure that local pathways are in place for psychological support following diagnosis, including access to rapid support for those who need it urgently.

4.3.3 Specifications for HIV testing services should require practitioners giving positive results to have appropriate competencies, with access to funded training and professional support as needed.

4.3.4 Where HIV testing services are provided in the community or non-HIV-specialist medical settings, commissioners should be clear about roles and responsibilities of different organisations or teams involved (eg it is possible that clinical staff providing testing will give the results but staff from a voluntary sector partner, if in the community, or GUM department, if in a hospital, would provide immediate emotional support).

4.4 Auditable indicators

4.4.1 Proportion of people newly diagnosed with HIV who are offered appropriate psychological support. Of those who accept a referral, the proportion who receive it a) within 48 hours, and b) within two weeks, of diagnosis.
(Measurable, where possible, through audit of records in services providing testing and/or through service user feedback.)

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STANDARD 5

Identifying psychological support needs

People living with HIV (PLWH) should have access to regular screening to identify if they have psychological support needs.

5.1 Recommendations

5.1.1 Screening for the presence of psychological difficulties

PLWH should have access to screening for the presence of symptoms of depression, anxiety, drug and alcohol misuse, acute stress disorder and risk of self-harm within the first three months of receiving an HIV diagnosis. It is essential for pathways to be in place for further assessment following screening for those who need them.

5.1.2 Screening for the presence of cognitive difficulties

PLWH should have access to screening for cognitive difficulties within the first three months of receiving an HIV diagnosis.

5.1.3 Repeat screening

PLWH should have access to repeated screening following events which are known to trigger or exacerbate psychological distress or cognitive difficulties, and otherwise on an annual basis.

5.1.4 Referral following screening

PLWH whose screen suggests significant difficulties should be offered referral to a suitably competent practitioner for further assessment.

5.2 Rationale

5.2.1 Screening for the presence of psychological difficulties

Many individuals are able to adjust to, and cope with, living with HIV with little need for psychological support. However some people experience difficulties and may struggle to seek out or access further support. Psychological distress and specific mental health difficulties in PLWH are frequently underrecognised by providers[1] and sometimes underreported by PLWH[2].

Services should therefore provide a process for systematically identifying those individuals who need psychological support. Screening usually entails asking individuals a set of structured questions to identify whether referral for a more in-depth assessment is needed. It should be distinguished from formal psychological assessment, which is a more thorough and comprehensive process of gathering information

for the purpose of making a diagnosis and/or formulating a person's psychological problems.

Screening on its own does not improve outcomes: it must be part of a framework or process of ongoing care, provided by staff with appropriate competencies[3] (see Standard 6). If used diagnostically without a care pathway for further assessment or multidisciplinary team discussion, there is a risk of overidentification of psychological problems.

Screening for psychological difficulties should be offered and delivered with sensitivity and care, to avoid further stigmatising those already living with HIV-related stigma (see Standard 1). Gathering information about PLWH's present circumstances, psychosocial history and previous use of mental health services provides a context for the interpretation of the screening results.

The early detection and treatment of psychological difficulties in people living with long-term health conditions can improve health outcomes and psychological wellbeing, and reduce the need for more frequent and costly medical interventions[4,5]. Screening for particular mental health problems and drug and alcohol use is a recommended part of routine clinical care for individuals at higher risk[6,7,8]. Screening PLWH for psychological difficulties can help practitioners to target limited resources cost-effectively[9], in view of the high prevalence rates of depression and psychological distress in this population[10,11,12,13].

Baseline screening of all people newly diagnosed with HIV, for a specific range of problems that most commonly occur in PLWH, enables the rapid identification of individuals:

- with pre-existing or current psychological difficulties who require fast-tracked referral for further assessment
- whose mental health is at risk of deteriorating due to a negative psychological reaction eg acute stress or severe depression, following diagnosis
- who can benefit from low-intensity interventions, as in levels 1 and 2 of the stepped care model (see page 22)
- who require onward referral for alcohol or substance misuse problems.

Certain screening tools can be administered and scored by practitioners without formal mental health training. Some can also be self-administered depending on language skills and cognitive abilities. Screening can take place in multiple settings, ranging from HIV clinics to community settings. However, screening of certain individuals, including those who are known to be cognitively impaired, have learning disabilities, language or literacy problems, sensory difficulties, or who are known survivors of trauma, should only be undertaken by staff with increased levels of specialisation.

Many of the screening tools described by New York State Department of Health AIDS Institute[14] are already routinely used in a broad range of UK healthcare settings and are therefore also appropriate for use in HIV care settings in the UK.

5.2.2 Screening for the presence of cognitive difficulties

Screening for cognitive difficulties is recognised as an area that needs increased attention as HIV can result in neuropsychological impairment[15]. Cognitive difficulties are often underestimated by clinicians, even in comparison to patient self-report[16].

Screening for cognitive difficulties should occur within three months of diagnosis. There are very quick ways of screening for cognitive difficulties in HIV infection, including brief screening questions[17,18] to help identify the need for more in-depth assessment.

Tools used should be appropriate for the population served. Non-HIV specialists, such as general practitioners, should be aware that cognitive screening tools used in general populations may not be appropriate for use in PLWH[19].

5.2.3 Repeat screening

As psychological difficulties are more common in people living with chronic health conditions[20], it is recommended that PLWH are re-screened at relevant points which are known to potentially trigger or exacerbate mental distress. These trigger points may or may not be directly related to HIV infection and its treatment, for example:

- significant changes in physical health status or disease progression
- initiation or change of treatment
- change of treatment centre
- after a period of non-attendance and loss of contact with treatment centre
- treatment failure
- varying adherence
- significant medication side-effects
- at times of co-infection, such as with hepatitis B/C or tuberculosis (TB)
- significant changes in psychosocial status
- distressing psychosocial problems (eg immigration difficulties)
- experience of stigma, violence or abuse
- bereavement or relationship problems
- family problems including those arising from children's HIV status.

Where there have been no trigger points, psychological screening once a year should form part of routine monitoring for PLWH. There should also be regular cognitive screening on an annual basis, as cognitive impairment can occur throughout the course of HIV infection[21].

5.2.4 Referral following screening

If screening suggests significant psychological or cognitive difficulties, a referral to a suitably qualified specialist for a more in-depth assessment must be triggered. The outcome of the in-depth assessment will allow for a joint treatment decision to be made according to the stepped care model (see page 22) and NICE guidelines.

Signposting to, or provision of, low-intensity support should also be available for PLWH whose screen demonstrates this level of need. This includes psycho-education (the provision of information about the likely causes and maintaining factors of current difficulties), peer support, self-help and community support.

5.3 Implications for commissioning and planning

5.3.1 In view of its multiple health and economic benefits, commissioners should ensure a regular screening programme for new and existing service users is included in specifications for HIV-specialist services. This should include provision for non-mental health-trained staff to be trained to administer screening tools.

5.3.2 If screening is to occur in non-HIV-specialist settings (eg primary care), non-HIV specialists require an awareness of the complex care needs that PLWH can present with and the high prevalence of psychological difficulties in PLWH. They also need an understanding of the social impact of living with HIV and associated issues such as sexual diversity and the impact of migration and asylum seeking.

5.3.3 Clear pathways for onward referral for more in-depth assessment of identified psychological and cognitive need must be developed. These pathways should take into consideration patient choice and preference.

5.4 Auditable indicators

5.4.1 Proportion of PLWH receiving screening for a) psychological and b) cognitive difficulties at least once a year.

5.4.2 Among PLWH whose screen suggests significant psychological or cognitive difficulties, the proportion referred for further assessment by a suitably competent professional.

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STANDARD 6

Competence to provide psychological support

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

6.1 Recommendations

6.1.1 Competence to provide psychological support

All individuals requiring psychological support should have this provided by skilled practitioners who have been appropriately trained and have demonstrated the necessary competencies[1,2,3,4,5,6].

6.1.2 Assessment of competence

Required standards, roles and competencies should be defined for all practitioners providing assessments and interventions across the spectrum of psychological support for PLWH. Agreed mechanisms should be in place for the assessment of competence according to these benchmarks[5].

6.1.3 Maintaining competence

Services providing psychological support for PLWH should ensure that their practitioners can demonstrate competence on an ongoing basis and should make provision to support the maintenance of competence through training, continuous professional development (CPD) and supervision[5,7].

Individual practitioners have a responsibility to ensure that they have received training and attained the required competencies before undertaking assessment or interventions to meet psychological support needs. They are also responsible for maintaining their competence on an ongoing basis but should be supported in this by their employing organisation[2,7].

6.1.4 Training

Specialists providing level 3 and level 4 psychological support (see stepped care model on page 22) should normally provide training, supervision and CPD for practitioners operating at levels 1 and 2[1,2,8]. Specialists should also receive training, supervision and CPD as appropriate to their role and profession in order to develop and maintain competencies at that level.

Accredited training courses in communication skills should be available for all practitioners who are working with PLWH. Advanced communication skills training should be undertaken by those who frequently have to break significant news including HIV test results, explain complex formulations or discuss distressing issues[5].

Training for the skills and competencies to deliver psychological support to PLWH should be

provided to augment generic training for psychological screening, assessment and interventions.

6.1.5 Required competencies

Competencies are required by practitioners providing psychological support at levels 1, 2, 3 and 4 in line with the stepped care model (see page 22).

In addition to generic competencies required by practitioners for their particular role and professional qualification, all practitioners providing psychological support for PLWH should have a demonstrable minimum set of competencies consisting of awareness and understanding about HIV and its impact on those living with the disease, including the cultural dimensions[1,3].

6.2 Rationale

6.2.1 Competence to provide psychological support

Effective psychological and cognitive screening, assessments and interventions require practitioners to be trained and competent in supporting people with HIV and to have access to expert advice as necessary. A variety of healthcare professionals, social care workers and other practitioners may be involved in the delivery of psychological support. While such practitioners can be from different disciplines, and competent in providing various aspects of psychological support to different levels, all should be trained, competent for their roles and provided with ongoing supervision, and/or be working within an appropriate clinical governance framework[2,6,7].

Where specific relevant competency frameworks, such as the 2004 *NHS Knowledge and Skills Framework*[5], exist for different professions and roles, these should be used as the basis for workforce development planning and assessment of competencies.

6.2.2 Assessment of competence

Whatever their role or profession, the competencies of practitioners who will provide psychological support should be assessed to ensure they are fit to practise. Professional groups have different ways of assessing competence. Generic competencies will often be demonstrated by professional qualifications. Professional vocational training will identify specific knowledge and skills against which competency can be assessed. Assessment should be evidence-based, eg by observation of practice, verbal feedback and a practitioner's portfolio of work[5,7,9].

6.2.3 Maintaining competence

Service providers have a responsibility to ensure that the practitioners they employ receive training and other appropriate education and support to maintain and increase their competencies. Practitioners are responsible for maintaining their own competence and for ensuring that they do not practise beyond their competence[2,7]. Training and competence levels should be reviewed on a regular basis[5,7].

6.2.4 Training

Psychological support should be an integral part of the role of every health and social care practitioner working with PLWH but for most, such support is not the focus of their practice. Many will require training in communication skills, breaking bad news, and recognising or screening for psychological distress[10].

Good communication skills underpin all elements of care[2] and will enable practitioners to discuss the needs and preferences of PLWH. Those who must communicate particularly complex or distressing information should have enhanced communication skills. There is some evidence to show that the communication skills of healthcare professionals can be improved by training[11,12]. Specialists in providing psychological support such as clinical and counselling psychologists can play a significant role in the development and maintenance of communication skills through teaching and training[5].

Practitioners whose primary role is psychological support may not be familiar with the needs specific to PLWH. They should have access to training on working with PLWH if their role requires it.

Some standardisation of content and quality of education provision is important to ensure high-quality psychological care.

6.2.5 Required competencies

In order to provide high-quality care for PLWH, all practitioners providing psychological support to PLWH should, in addition to the generic competencies for their role, have the following minimum competencies[1,5]:

- awareness of the diversity of needs that PLWH may have - especially men who have sex with men, those from minority ethnic communities, women and substance misusers - in order to promote effective communication
- awareness of the cultural dimensions of face-to-face communication, cultural sensitivities relating to HIV and its treatment, and cultural norms such as those relating to sexual practices
- demonstrable skills to interact appropriately with PLWH from a range of cultural backgrounds and of different sexualities
- an understanding of HIV disease including disease progression, symptoms and treatment regimens
- an understanding of the presentation of cognitive difficulties in HIV disease and its functional consequences
- an understanding of the psychological impact and sequelae of HIV disease
- an understanding of gender differences in the psychological impact of HIV disease
- knowledge of current guidance on how to prevent transmission (including vertical transmission) of HIV
- an understanding of the ethical and legal issues relating to HIV transmission
- an understanding of the implications of confidentiality and disclosure for PLWH, for example between healthcare providers or in the workplace
- knowledge of the range and diversity of local HIV service provision and related access and referral criteria
- an understanding of the roles of other provider organisations and practitioners who are involved in the psychological support of PLWH.

6.3 Implications for commissioning and planning

6.3.1 The expertise of the providers of level 4 psychological support should be harnessed to support the delivery of education, training and governance across the range of providers within HIV psychological support provision.

6.3.2 Commissioners and providers should ensure that:

- local education and training provision is adequate to ensure the workforce is appropriately skilled to meet the demands of all four levels of psychological support for PLWH (described on page 22)
- resources for adequate education and training are costed and included in commissioning agreements.

6.3.3 Contracts for all services commissioned to provide psychological support for PLWH should state requirements relating to education, training and assessment and maintenance of competencies.

6.4 Auditable indicators

6.4.1 Proportion of practitioners delivering psychological support to PLWH who have successfully completed competency-based training according to their scope of practice and fulfilled relevant CPD requirements.
(Measurable through audit across local providers of psychological support.)

6.4.2 Evidence of satisfactory assessment of competencies and appropriate professional registration of practitioners at levels 1 to 4 of the stepped care model.
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STANDARD 7

Coordination of psychological support

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

7.1 Recommendations

7.1.1 Service design

Psychological support should be included in the design, development and provision of all HIV treatment and care services across a local area. A coordinated range of psychological support interventions should be offered across the spectrum of local providers[1].

7.1.2 Pathways of care

Clear pathways should be developed between services providing HIV clinical treatment and care and those offering psychological support. Pathways should be explicit, agreed and adopted by all HIV clinical service providers[2].

Psychological support should be delivered through a network of providers with different levels and types of expertise in psychological issues for PLWH[3,4] (see stepped care model, page 22). Services should be planned to provide seamless integration across levels of psychological support and across providers, including transitions from services for families and young people to those for adults[5].

A pathway enabling PLWH to self-refer into psychological support services should be established.

Pathways should also be in place to ensure the availability of psychological support at all levels from practitioners with specialist expertise in HIV.

Service providers should establish pathways to ensure PLWH can access specialist level 3 and level 4 support as and when they need it[4]. Emergency psychiatric services should be available when required for PLWH with severe mental health problems in and out of normal working hours.

7.1.3 Leadership and collaboration

The provision of psychological support for PLWH should be strategically planned and coordinated across all relevant local providers. Such coordination requires collaboration across organisational and professional boundaries with clearly defined and accountable leadership and management arrangements. This may be achieved through HIV service networks or clinical networks where these are in place[1,6].

Clinical leadership of psychological support for people who use HIV treatment services should be

provided by practitioners who have level 4 psychological support skills with particular expertise in HIV[7,8,9,10]. Clinical leads should be part of the multidisciplinary clinical and management teams of services providing HIV care, collaborate with the professional leads of other local services providing psychological support for PLWH (eg social care and community support) and work closely with commissioners.

7.1.4 Service provision

Commissioners, clinical leads and other relevant stakeholders should work together to ensure that high quality psychological support services based on the needs of local PLWH are available, are delivered and are effectively coordinated.

7.2 Rationale

7.2.1 Service design

Psychological support for PLWH should be given equal priority with other aspects of their care and fully integrated with HIV diagnosis and treatment. Where HIV service networks or clinical networks are in place, consideration should be given to including psychological support for PLWH within their scope. Networks can facilitate equity of access and care quality across providers, as well as fostering multidisciplinary working and professional development.

7.2.2 Pathways of care

The psychological support needs of PLWH can be complex and appropriate psychological support for an individual may involve a variety of practitioners within health, social care and other community settings, whether in the statutory, voluntary or independent sectors. The full range of psychological support should be available for PLWH, regardless of the level of provision available within the services where they normally receive their HIV care. This should include access, when necessary, to local mental health services including psychiatric and community support, as well as to social and legal services[4,11].

Coordination of all aspects of care is therefore imperative, with effective pathways agreed and in place between providers[5], so that PLWH can move between services as needed and receive psychological support that is seamless from their perspective.

7.2.3 Leadership and collaboration

While commissioners should ensure services are commissioned in line with local strategies and needs assessment, their work needs to be informed by the frontline experience and professional knowledge of expert practitioners, and the in-depth understanding they can bring of the capacity and competencies of local service providers[10]. Commissioners should work closely with service providers, through networks where appropriate, to understand local needs and plan the provision of high-quality care through coordinated services. Collaborative arrangements, through formal networks or other frameworks, should be centred around the needs of PLWH to ensure these needs are met wherever they access psychological support in healthcare, social care or community support services.

Specialist expertise in psychological support for PLWH is required to provide effective clinical leadership for psychological support services. Clinical leads should maintain close contact with clinical practitioners who are actively involved in the care or support of PLWH and ensure they are enabled to provide psychological support at an appropriate level as part of their role.

7.2.4 Service provision

Where coordination of service provision at strategic and operational levels is missing, PLWH may be denied access to appropriate services for a variety of reasons[11]. These include:

- a failure to recognise the psychological support needs of PLWH
- a failure of clinical providers to actively investigate the psychological support needs of PLWH
- a failure of PLWH to access existing services due to their lack of familiarity with them
- a failure of accessed services to meet fully the psychological support needs of PLWH due to inadequate communication
- a lack of appropriate services due to limitations in planning, funding or workforce capacity.

To overcome these risks, it is important to ensure strategic and operational coordination, which will lead to improved quality of life for PLWH and their higher satisfaction with services.

For the provision of coordinated and high-quality psychological support services, commissioners, clinical leads and other relevant stakeholders should ensure:

- the demographic profile of the local population of PLWH is understood in order to ensure that its needs are adequately met
- the diversity of the needs of PLWH is taken into consideration when developing network protocols
- strategies are in place to identify and meet the needs of local PLWH who have difficulty accessing services
- PLWH are involved as equal partners with professionals in the development and provision of psychological support (see Standard 3)
- decisions on service configuration and on developmental priorities are informed by needs assessment and clinical expertise
- resources are available for psychological support provision to be age and gender appropriate and available in languages used by the local community, with specific attention paid to issues affecting ethnic minority groups, asylum seekers and refugees, survivors of trauma and those with sensory impairment, learning disabilities or mental health problems[10]
- resources are available for education and training sufficient to maintain required competencies
- mechanisms are established to support effective partnerships between the statutory, voluntary and (where relevant) independent sectors to ensure PLWH receive coordinated and cost-effective care
- operational policies, care pathways and referral guidelines are developed in partnership between providers of psychological support in healthcare, social care and other community settings, including those in the voluntary sector
- effective multidisciplinary and multi-agency communication and joint working allow the HIV-specific psychological support needs of PLWH to be met.

7.3 Implications for commissioning and planning

7.3.1 Commissioners should support and engage with clinical leads of psychological support services to plan and resource the provision of coordinated psychological support for PLWH across a geographical area. Ensuring a comprehensive range of services to meet the varied psychological support needs of PLWH may require supra-local commissioning arrangements.

7.3.2 Commissioning and planning of high-quality psychological support will require:

- assessment of the local need in terms of the prevalence, complexity and diversity of psychological and cognitive problems in PLWH, and of the resources and competencies and training required to meet these needs
- assessment of existing service provision in terms of resources, psychological support and HIV-specialist workforce and competencies
- mapping of available psychological support provision to the established psychological need
- development of contracts for comprehensive provision of psychological support based on the results of the mapping procedure
- development of care pathways including the defining of provider roles, referral criteria, protocols, capacity, clinical governance, and performance outcomes and an understanding of more specialist services for onward referral
- regular appraisal and determination of training requirements for all those providing psychological support
- access to training, supervision or other effective means of ongoing support for all practitioners providing psychological support
- regular audits of the availability and appropriateness of psychological support to ensure that the required standards are met and to inform workforce development
- a seamless interface between psychological support providers and other providers of HIV care through regular communications and case note access where appropriate
- development of a directory of psychological support services to be available to health and social care practitioners and other relevant providers. This should include information about the scope of services and detail about how each can be accessed. The directory should be updated regularly and a full review conducted annually.

7.4 Auditable indicators

7.4.1 Evidence of inclusion of psychological support at levels 1, 2, 3 and 4 in agreed care pathways at each HIV treatment centre.
(Measured through regular review of care pathways.)

7.4.2 Representativeness of those referred to and/or accessing psychological support according to service and local profiles (eg gender and ethnicity).

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STANDARD 8

Evidence-based practice

All psychological assessment and interventions for people living with HIV (PLWH) should be based on the best available evidence.

8.1 Recommendations

8.1.1 Evidence-based assessment and interventions

All psychological assessment methods and psychological support interventions used across the four levels of stepped care should be selected and delivered according to the best available evidence of effectiveness.

8.1.2 HIV-appropriate assessment and intervention methods

Methods used for psychological and cognitive assessment and psychological support interventions for PLWH should have been developed, standardised and evaluated for use with HIV and/or other life-threatening long-term medical conditions.

8.2 Rationale

8.2.1 Evidence-based assessment and interventions

Evidence-based practice is defined as decision-making based on sound research evidence that is combined with individual practitioner expertise. It also takes into consideration the needs of the individual service user. The goal of evidence-based practice is to improve outcomes for the service user, enhance quality of care, and provide some standardisation of treatment and other interventions. Using evidence-based interventions also improves cost-effectiveness, by avoiding expenditure on those which do not work or work less well than others.

The scientific and healthcare community grades the strength of evidence for the effectiveness of interventions into three or four levels, according to the robustness of the research methodology used. Level 1 refers to randomised controlled trials (RCTs) which are generally accepted as the gold standard, providing the most reliable evidence. However, this level of evidence for psychological support interventions in HIV is relatively rare.

The most prevalent types of evidence for psychological support interventions in HIV include non-randomised clinical trials, observational case studies and general consensus from experts.

Existing evidence-based guidelines should be used to inform practice in psychological support for PLWH. In order to create realistic and relevant best practice guidelines for psychological assessment and support for PLWH, all levels of evidence need to be considered. Given the limited availability of RCT evidence, other

research designs such as qualitative and outcomes research are becoming recognised as meaningful ways of providing evidence. However, clinical or other service provision experience and judgement will always be needed to inform practice especially where relevant evidence is thin, non-existent or not directly relevant to the needs of an individual PLWH.

No assessment method or intervention can be described as evidence-based for all populations and communities. The vast majority of studies have been conducted with white American or British populations so their applicability to other communities is questionable. A number of experts have recently called for 'culturally modified' psychological interventions, including cognitive behavioural therapy (CBT)[1,2,3]. However, there is no consensus as to what modifications need to be made, nor have they been systematically evaluated in the UK. Therefore, an evidence base for CBT and other psychological therapies across all communities affected by HIV is not currently available. Given these limitations, involving service users from all communities affected by HIV in the evaluation of assessment methods and interventions is recommended.

8.2.2 HIV-appropriate assessment and interventions

Assessment takes place at all levels within the stepped care model (see page 22). Regardless of the provider and their level of expertise in HIV, it is important that assessment is performed in a way that has been shown through research and evaluation to be effective with PLWH, in order to ensure PLWH receive appropriate referrals for psychological support interventions.

8.3 Implications for commissioning and planning

8.3.1 Commissioners should involve public health, clinical and community experts to ensure commissioning and provision of psychological support is informed by up-to-date evidence of effectiveness and current evidence-based guidelines.

8.3.2 Local health and social care needs assessments relevant to HIV and mental health respectively should include assessment of the psychological support needs of PLWH.

8.3.3 Adequate resources should be made available for the continual evaluation and development of assessment methods and psychological support interventions for PLWH.

8.4 Auditable indicators

8.4.1 Adherence by services providing psychological support for PLWH to evidence-based guidelines of best practice as set by organisations such as the National Institute for Health and Clinical Excellence (NICE).

8.4.2 Evidence that services providing psychological support for PLWH are using assessment and intervention methods developed, standardised and evaluated for use with HIV or other long-term medical conditions.

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See also systematic reviews of evidence listed in Appendix D.

Auditable outcomes and indicators

Measuring outcomes of psychological support

Access to high-quality psychological support, as set out in these standards, will contribute to improvements in both mental health and physical health outcomes in PLWH, as well as reductions in onward transmission of HIV and the rate of new infections. It is important to measure these outcomes and this will provide a high-level assessment of whether the standards for psychological support (and other standards and guidelines relevant to the care of PLWH) are being implemented in an effective way.

The domains in the Government's three proposed outcomes frameworks, for the NHS, public health and social care respectively[1,2,3,4] include indicators relevant to mental health and physical health. Progress against these (and any future indicators likely to be developed as better data on mental health outcomes become available[5]) should be assessed amongst PLWH, taking account of any particularities associated with HIV which may affect what and how best to measure.

At local and national level, ongoing surveillance and specific audits can measure health outcomes for PLWH and adherence to standards and guidelines designed to improve these outcomes.

Outcomes to which psychological support for PLWH contributes

Psychological support both improves individual health outcomes and reduces the risk of onward transmission of HIV through its positive impact on:

- adherence to antiretroviral therapy
- retention in HIV treatment
- avoidance of risk behaviour.

Psychological support for PLWH also reduces:

- number of hospital admissions
- length of inpatient stays
- time in medical consultations
- number of medical investigations.

Thus audits to measure progress against these factors will provide an indication of the impact of the standards and their implementation, as one contribution among the full range of health, social care and preventive interventions.

Such audits are important in measuring both health outcomes and cost efficiencies, and are relevant in relation to the productivity and prevention elements of the QIPP framework[6].

Overarching outcomes of psychological support

Measuring mental health outcomes is a way of assessing more directly the impact of psychological support. Outcome measures developed to assess the mental health and wellbeing of the general population or of

people living with other long-term conditions may be useful, though not all will be suitable for use in PLWH.

It is suggested that the following overarching outcomes should be assessed in PLWH as a measure of the effectiveness of psychological support in line with these standards. The development and testing of specific indicators and tools to measure these outcomes is recommended if they are not already in place.

1. Levels of psychological morbidity, quality of life and wellbeing.
(Measured regularly using HIV-appropriate and culturally sensitive measures, including surveys of service users.)

2. Satisfaction of PLWH with:
- the response of services to their psychological support needs
- the coordination of psychological support
- the impact of psychological support on their quality of life and wellbeing.

(Measured through qualitative and quantitative methods for one-off 'snapshots' or undertaken regularly for trends over time.)

Auditable indicators for each standard

In addition to the overarching outcomes suggested above, the use of specific indicators is recommended to measure how well each individual standard is being met. As such, the suggested indicators below (reproduced in each respective standard) are a mixture of process and outcome measures. Defined simply, 'process' indicators measure what service providers do, whereas 'outcome' indicators measure the results for service users.

Other indicators may be identified at local level depending on strategic priorities and the logistics of data collection. The development of a local 'scorecard' may be helpful to monitor progress against a set of indicators over time.

The indicators below suggest what can be measured to assess the quality of care and progress over time. They do not propose benchmarks or targets to be achieved, as these will need to be determined according to local circumstances and progress to date.

Standard 1: promotion of mental health and psychological wellbeing

1.4.1 Proportion of service users who report that:
a) their service providers give them sufficient opportunity to discuss their psychological wellbeing
b) their service providers understand the experience of living with HIV
c) they have experienced stigma from healthcare practitioners in the last year
d) they receive information about HIV and their care which makes them feel better.
(Measurable through surveys of service users.)

1.4.2 Evidence that accurate, evidence-based information is provided within services for PLWH, including information in languages and formats to meet local needs and information materials from accredited providers.
(Measurable through observation and surveys of service users.)

Standard 2: comprehensive psychological support services

2.4.1 When psychological support needs have been identified, the proportion of PLWH who have been referred on to appropriate psychological support.
(Measurable through occasional fixed-period audit of service user records in HIV treatment centres and community support organisations.)

2.4.2 Proportion of PLWH, in whom a serious and immediate risk of harm to self or others has been identified through screening or clinical observation, who are referred to emergency mental health services on the same day.
(Measurable through audit of service user records.)

Standard 3: engagement of people living with HIV

3.4.1 Evidence from providers of HIV-specialist psychological support that they have:
a) developed a plan for engaging PLWH
b) implemented the plan
c) taken action in response to PLWH input.

3.4.2 Inclusion of patient-reported outcome measures (PROMs) and/or patient-reported experience measures (PREMs) in audits and evaluations of psychological support provision.

Standard 4: support at the time of diagnosis

4.4.1 Proportion of people newly diagnosed with HIV who are offered appropriate psychological support. Of those who accept a referral, the proportion who receive it a) within 48 hours, and b) within two weeks, of diagnosis.
(Measurable, where possible, through audit of records in services providing testing and/or through service user feedback.)

4.4.2 Evidence of a clear and agreed pathway for post-diagnostic psychological support from services providing HIV testing.

Standard 5: identifying psychological support needs

5.4.1 Proportion of PLWH receiving screening for a) psychological and b) cognitive difficulties at least once a year.

5.4.2 Among PLWH whose screen suggests significant psychological or cognitive difficulties, the proportion referred for further assessment by a suitably competent professional.

Standard 6: competence to provide psychological support

6.4.1 Proportion of practitioners delivering psychological support to PLWH who have successfully completed competency-based training according to their scope of practice and fulfilled relevant CPD requirements.
(Measurable through audit across local providers of psychological support.)

6.4.2 Evidence of satisfactory assessment of competencies and appropriate professional registration of practitioners at levels 1 to 4 of the stepped care model.
(Measurable through audit across local providers of psychological support.)

Standard 7: coordination of psychological support

7.4.1 Evidence of inclusion of psychological support at levels 1, 2, 3 and 4 in agreed care pathways at each HIV treatment centre.
(Measured through regular review of care pathways.)

7.4.2 Representativeness of those referred to and/or accessing psychological support according to service and local profiles (eg gender and ethnicity).

Standard 8: evidence-based practice

8.4.1 Adherence by services providing psychological support for PLWH to evidence-based guidelines of best practice as set by organisations such as the National Institute for Health and Clinical Excellence (NICE).

8.4.2 Evidence that services providing psychological support for PLWH are using assessment and intervention methods developed, standardised and evaluated for use with HIV or other long term medical conditions.

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APPENDIX A

Glossary

Assessment	1. Evaluation of a person using selected skills of history-taking; physical examination, laboratory, imaging, and social evaluation, to achieve a specific goal. 2. Appraisal or analysis of conditions, disorders, data, or a person's overall state.
Clinical psychology	Clinical psychology aims to reduce psychological distress and to enhance and promote psychological well-being by the systematic application of knowledge derived from psychological theory and data.
Cognitive	Pertaining to cognition, ie the mental activities associated with thinking, learning, and memory.
• 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.
• difficulties	People who have cognitive difficulties may have short or long-term memory problems and experience difficulties in starting things, making decisions, planning and organising.
• functioning	Any mental process that involves symbolic operations eg perception, memory, creation of imagery, and thinking. Cognitive functioning encompasses awareness and capacity for judgment, problem solving and decision-making.
• impairment	Mental disorders distinguished by a limitation of mental functions (eg memory, comprehension and judgment). Impairments range from subtle, such as difficulty remembering appointments or staying focussed at work, through to severe impairments in understanding, memory or behaviour that require high levels of support.
• rehabilitation	Cognitive rehabilitation is the term used to describe the non-medical treatment of cognitive impairment. It includes a range of approaches and techniques typically involving services provided by occupational therapists, clinical psychologists, neuro-psychologists and speech and language therapists.
• screening	Cognitive screening is a "first step" in detecting dementia and other neuropsychiatric syndromes.
Cognitive behavioural therapy (CBT)	A psychotherapeutic approach or form of talking therapy. CBT aims to solve problems concerning dysfunctional emotions, behaviours and cognitions through a goal-oriented, systematic procedure.
Counselling psychology	Counselling psychology is a branch of applied professional psychology. It has its origins in the UK within the humanistic movement with influences from counselling psychology in the USA and European psychotherapy on the one hand; and the science of psychology (cognitive, developmental, and social) on the other.

Counselling and psychotherapy	Counselling and psychotherapy are umbrella terms used to cover a range of talking therapies. Counselling and psychotherapy are services sought by clients to help them resolve emotional, psychological and relationship issues within a context of confidentiality and clear ethical boundaries using evidence-based practices to foster long-term recovery and increased wellbeing.
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 persons' 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	Health psychology is 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 health care system • the formulation of health policy.
Liaison psychiatry	Liaison psychiatry is the sub-specialty which provides psychiatric treatment to people attending general hospitals, whether they attend outpatient clinics, accident & emergency departments or are admitted to inpatient wards. Therefore it deals with the interface between physical and psychological health.
Low-intensity support	Emotional/social support: including mutual support networks, befriending services, home-visiting services, telephone support services and 'virtual' (ie computer-mediated) social support. Such services are primarily designed to provide companionship and emotional support or to extend social networks for people living alone. They can be either temporary or long-term, usually depending on the user group.
Mental health	WHO definition: "a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community."
• service	Hospital (acute) or community service providing multidisciplinary psychiatric care.
• specialists	Practitioners within NHS mental health system, specifically clinical psychologists, psychiatrists and psychiatric (or mental health) nurses.
• team	Multidisciplinary team of mental health specialists within NHS services ie psychologists, psychiatrists and psychiatric (or mental health) nurses. Mental health teams may be based in community or hospital settings.
Neurocognitive	A term used to describe cognitive functions closely linked to the function of particular areas, neural pathways, or cortical networks in the brain.

• disorder or problem	A reduction or impairment of cognitive function in one of these areas, but particularly when physical changes can be seen to have occurred in the brain, such as after neurological illness, mental illness, drug use, or brain injury.
• functioning	See cognitive functioning.
Neurorehabilitation	A process whereby people who suffer from impairment following neurologic diseases regain their former abilities or, if full recovery is not possible, achieve their optimum physical, mental, social and vocational capacity.
Peer support	Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. Peer support is not based on psychiatric models and diagnostic criteria. It is about understanding another's situation empathically through the shared experience of emotional and psychological pain. For the purposes of this document, peer support for PLWH means support provided by other PLWH.
Practitioner	For the purposes of this document, anyone providing psychological support. This has been chosen as an inclusive term which encompasses a wide range of health and social care professionals as well as others such as community and peer support workers.
Psychoeducation	Psychoeducation is a form of education which provides information about the likely causes and maintaining factors of current psychological difficulties and strategies to deal with these.
Psychological:	
• assessment	The psychological assessment is a structured procedure that gathers information from and/or tests a person to evaluate an emotional, cognitive or behavioural complaint.
• disorder	A psychological disorder, also known as a mental disorder, is a pattern of behavioural or psychological symptoms that impact multiple life areas and/or create distress for the person experiencing these symptoms.
• screening	Asking individuals a set of structured questions to identify whether referral for a more in-depth assessment is needed. It may also indicate a need for signposting to low-intensity support.
• support	For the purposes of this document, any form of support which is aimed at helping PLWH to enhance their cognitive, emotional and behavioural wellbeing.
• symptoms	A subjective manifestation of a pathological condition. Symptoms are reported by the affected individual rather than observed by the examiner.
• therapy/therapist	An inclusive term covering anyone with therapeutic training of whatever model including psychodynamic, cognitive behavioural, arts-based and systemic approaches.

Psychiatry/psychiatric	Psychiatry is the medical science of diagnosing and treating mental health problems with a range of interventions, most commonly drugs and psychotherapies (and much less frequently other procedures such as electro-convulsive therapy (ECT) and exceptionally surgical interventions). Psychiatrists are in addition trained in the assessment and use of legal processes where they interface with physical and mental health.
Psychotherapy	See counselling and psychotherapy.
Risk assessment (health)	A method of describing a person's chance of falling ill or dying of a specified condition, based on actuarial calculations that compare the chances of acquiring the condition with those of the general population expressed as the expected age at which death or disease will occur, and intended as a way of drawing the person's attention to the probable health consequences of risky behaviour.
Quality of life	Individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. (WHO, 1997)
Screening	Screening tests or enquiries detect people at risk of having the condition or at risk of developing the condition in the future. They do not establish a diagnosis but give some indication of any action that may be required, such as further diagnostic investigation, closer monitoring or even preventative action. (NICE, 2009)
Self-help	Otherwise known as self-improvement, refers to the acts of an individual to improve himself or herself without assistance from anyone else. The term refers to any measure used to improve mental, physical, financial or spiritual conditions alone or by means of books or other reference materials.
Self-management	Learning and practising skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition. The NHS Expert Patient Programme uses the term to refer to "any formalised patient education programme aimed at providing the patient with the information and skills necessary to manage their condition within the parameters of the medical regime."
Support agencies	General term for agencies, often in the voluntary sector, providing support for PLWH, usually to meet needs complementary to medical care including psychological and social support.
Wellbeing (mental/ cognitive/emotional/ behavioural)	A good or satisfactory state of existence, characterised by health, happiness, education, recreation and leisure time, and social belonging.

APPENDIX B

Abbreviations

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
BACP	British Association for Counselling and Psychotherapy
BASHH	British Association for Sexual Health and HIV
BHIVA	British HIV Association
BIS	British Infection Society (now known as British Infection Association)
BME	Black and minority ethnic
BPS	British Psychological Society
CBT	Cognitive behavioural therapy
CPD	Continuing professional development
DH	Department of Health
FacHIV&SH	Faculty of HIV & Sexual Health (of the BPS)
FSRH	Faculty of Sexual and Reproductive Healthcare (of the RCOG)
GHT	George House Trust
GIPA	Greater Involvement of People Living with AIDS (now with HIV)
GUM	Genitourinary Medicine
HIV	Human immunodeficiency virus
HPA	Health Protection Agency
HPC	Health Professions Council
IAPT	Improving Access to Psychological Therapies
LGBT	Lesbian, gay, bisexual and transgender
MedFASH	Medical Foundation for AIDS & Sexual Health
MSM	Men who have sex with men
NAT	National AIDS Trust
NHIVNA	National HIV Nurses Association
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NYSDOH	New York State Department of Health
PbR	Payment by Results
PCT	Primary care trust
PPE	Patient and public engagement
PREM	Patient-reported experience measure
PROM	Patient-reported outcome measure
PTSD	Post-traumatic stress disorder
PWLH	Person (or people) living with HIV
QIPP	Quality, Innovation, Productivity and Prevention
RCGP	Royal College of General Practitioners
RCOG	Royal College of Obstetricians and Gynaecologists
RCP	Royal College of Physicians
RCPsych	Royal College of Psychiatrists
RCT	Randomised control trial
SSHA	Society of Sexual Health Advisers

TB	Tuberculosis
THT	Terrence Higgins Trust
UNAIDS	United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development
WHO	World Health Organization

APPENDIX C

Professionals and peers that may be involved in providing psychological support

- Arts therapists
- Benefits advisers
- Care workers
- Child psychologists
- Child and adolescent psychiatrists
- Clinical psychologists
- Community HIV testing service workers
- Community support volunteers
- Community HIV support workers
- Complementary therapists
- Counselling psychologists
- Counsellors
- District nurses
- Drugs workers
- Educational psychologists
- Emergency and acute medicine doctors
- Faith leaders
- Family therapists
- General and community psychiatrists
- General practitioners
- General practitioners with special interest
- Health promotion specialists
- Health psychologists
- Health trainers
- Healthcare assistants
- Helpline workers
- HIV nurses including clinical nurse specialists
- HIV-specialist hospital doctors
- Hospital ward nurses
- Housing advisers
- Immigration advisers
- Liaison psychiatrists
- Life coaches
- Mental health nurses including clinical nurse specialists
- Neuropsychologists
- Nurse counsellors
- Nurses in non-HIV specialties caring for PLWH
- Occupational psychologists
- Occupational therapists
- Outreach workers
- Peer support workers
- Physiotherapists
- Practice nurses
- Prison healthcare staff
- Psychiatric nurses
- Psychosexual practitioners
- Psychotherapists
- Sex therapists
- Sexual and relationship therapists
- Sexual and reproductive healthcare doctors and nurses
- Sexual health advisers
- Social workers
- Specialist hospital doctors – non-HIV
- Speech and language therapists
- Support group workers
- Welfare advisers

APPENDIX D

Additional reading

Each section of this publication contains references and further supporting documents, and these are also gathered together in the bibliography. The suggested additional reading below comprises three key publications bringing together much of the relevant evidence supporting these standards.

National AIDS Trust (2010) *Psychological support for people living with HIV*. London: National AIDS Trust.
www.nat.org.uk/Media%20library/Files/Policy/2010/Psychological%20support%20July%202010%20updated.pdf
This report of an expert seminar, which followed a focus group exercise with PLWH, outlines many of the issues and concerns which led to the development of these standards.

Psychology, Health and Medicine (October 2011) Volume 16, Issue 5 Special Issue: Mental Health Considerations in HIV and AIDS.
http://www.tandfonline.com/toc/cphm20/current
A series of systematic reviews providing a comprehensive overview of the evidence relating to psychological support needs among PWLH and the effectiveness of interventions to address them, as follows:

- Catalan J, Harding R, Sibley E et al (2011) HIV infection and mental health: Suicidal behaviour – Systematic review. *Psychol Health Med* **16**(5):588-611. doi:10.1080/13548506.2011.582125
- Clucas C, Sibley E, Harding R et al (2011) A systematic review of interventions for anxiety in people with human immunodeficiency virus. *Psychol Health Med* **16**(5):528-547. doi:10.1080/13548506.2011.579989
- Harding R, Liu L, Catalan J et al (2011) What is the evidence of interventions to enhance coping among people living with HIV disease? A systematic review. *Psychol Health Med* **16**(5):564-87. doi: 10.1080/13548506.2011.580352
- Rackstraw S (2011) HIV-related neurocognitive impairment – A review. *Psychol Health Med* **16**(5):548-563. doi:10.1080/13548506.2011.579992
- Sherr L, Clucas C, Harding R et al (2011) HIV and depression – a systematic review of interventions. *Psychol Health Med* **16**(5):493-527. doi:10.1080/13548506.2011.579990
- Sherr L, Nagra N, Kulubya G et al (2011) HIV infection associated post-traumatic stress disorder and post-traumatic growth - a systematic review. *Psychol Health Med* **16**(5):612-619. doi:10.1080/13548506.2011.579991

Psychosomatic Medicine (June 2008) Special issue: Psychosocial Influences in HIV/AIDS: Biobehavioral Mechanisms, Interventions, and Clinical Implications.
This issue of the Journal of the American Psychosomatic Society contains an introduction by the guest editors, an HIV overview and a series of articles under the following headings:

- psychosocial influences
- biobehavioral mechanisms
- treatment and preventive interventions.

APPENDIX E

Working Party membership

NAME	ROLE	REPRESENTING (PROFESSIONAL BODIES)
Elizabeth Shaw, Chair	Consultant Clinical Psychologist, Barnet, Enfield and Haringey Mental Health Trust, London	Faculty for HIV & Sexual Health, Division of Clinical Psychology, British Psychological Society
Jane Anderson	Consultant Physician, Director, Centre for the Study of Sexual Health and HIV, Homerton University Hospital, London	British HIV Association
Yusef Azad	Director of Policy and Campaigns, National AIDS Trust, London	
Ravneet Batra	Consultant Psychiatrist, Regional Infectious Diseases Unit, Western General Hospital, Edinburgh	
Tina Campbell	Head of Counselling Services, Sandyford, NHS Greater Glasgow and Clyde	British Association for Counselling and Psychotherapy
Jose Catalan	Consultant Liaison Psychiatrist, South Kensington & Chelsea Mental Health Centre, London	
Dennis Dobbin	Lead Community Psychiatric Nurse, CASCAID Team, South London and Maudsley NHS Foundation Trust	National HIV Nurses Association
Hannah Drinkwater	London Operations Manager, Long-Term Conditions Management, Terrence Higgins Trust, London	
Simon Edwards	GU/HIV Clinician, Mortimer Market Centre, NHS Camden Provider Services, London	British Association for Sexual Health and HIV and British HIV Association
Ceri Evans	Senior Sexual Health Adviser, West London Centre for Sexual Health, Charing Cross Hospital, London	Society of Sexual Health Advisers
Stuart Gibson	Consultant Clinical Psychologist, South London & Maudsley NHS Foundation Trust	Faculty for HIV & Sexual Health, Division of Clinical Psychology, British Psychological Society
Barbara Hedge	Consultant Clinical Psychologist, Head of Psychology Services, St Helens and Knowsley Teaching Hospitals NHS Trust	Faculty for HIV & Sexual Health, Division of Clinical Psychology, British Psychological Society
Philip Henshaw	Acting Head of Psychology, Infection and Immunity, Barts and the London NHS Trust	Faculty for HIV & Sexual Health, Division of Clinical Psychology, British Psychological Society
Nicola Jacobs	(former) Policy Officer, National AIDS Trust, London	
Philippa James	General Practitioner, Boundary Medical Practice, Hulme, Manchester	Royal College of General Practitioners

Ewan Jenkins	Sexual Health Commissioning Manager, Inner North West London Primary Care Trusts	
Sharon Kalsy	Consultant Clinical Psychologist & Clinical Services Director, GamCare/GamCare Trade Services, London	Faculty for HIV & Sexual Health, Division of Clinical Psychology, British Psychological Society
Ruth Lowbury	Chief Executive, Medical Foundation for AIDS & Sexual Health (MedFASH), London	
Alexander Margetts	Clinical Psychologist, South Kensington & Chelsea Mental Health Centre, London	Faculty for HIV & Sexual Health, Division of Clinical Psychology, British Psychological Society
Audrey Matthews	Chartered Clinical Psychologist, Chalmers Sexual Health Centre, Edinburgh	Faculty for HIV & Sexual Health, Division of Clinical Psychology, British Psychological Society
Diane Melvin	Consultant Clinical Psychologist to Family HIV Service, St Mary's Hospital, London	Children's HIV Association
Chris Morley	(former) HIV Policy, Information and Publications Coordinator, George House Trust, Manchester	
Andrew Pearmain	HIV Consultant Practitioner, Adult Social Care, Essex County Council	
Jenny Petrak	Consultant Clinical Psychologist, Imperial College Healthcare – Cancer Services, London	Faculty for HIV & Sexual Health, Division of Clinical Psychology, British Psychological Society
Simon Rackstraw	Medical Director, Mildmay UK, London	
Christopher Sandford	Patient Representative, Bloomsbury Clinic, Mortimer Market Centre, London	
Lorraine Sherr	Professor of Clinical and Health Psychology and Head of Health Psychology Unit, Research Department of Infection & Population Health, Royal Free and University College Medical School, London	
Flick Thorley	Clinical Nurse Specialist HIV and Mental Health, Department of Psychological Medicine, Chelsea and Westminster Hospital, London	
Jason Warriner	Service Governance and Quality Director, Terrence Higgins Trust, London	Royal College of Nursing
Edwina Williams	Consultant Liaison Psychiatrist, South Kensington & Chelsea Mental Health Centre, London	Royal College of Psychiatrists
Sarah Zetler	Lead Clinical Psychologist, Department of Sexual Health, Homerton University Hospital NHS Trust, London	Faculty for HIV & Sexual Health, Division of Clinical Psychology, British Psychological Society

APPENDIX F

Community service provider meeting attenders

Community service provider organisations were invited, via the NAT HIV Policy Network, to provide input at an early stage of the standards' development. The following organisations attended a meeting in December 2010.

Attended in person:	**On behalf of**
Steve Worrall Angela Byrne	Positive East
Chris Morley	George House Trust
Nimisha Tanna Alison Smith	Body and Soul
Nicola Jacobs	National AIDS Trust
William Chappel	Terrence Higgins Trust

By teleconference:	
Jenny Hand	Leicestershire AIDS Support Services
Rory Thompson	The HIV Support Centre (Belfast)
Brian Bridger	Positive Action Hampshire

APPENDIX G

Consultation responses received

The following persons and organisations responded to the consultation draft of the standards.

Abbott Laboratories UK
African Health Policy Network
Andy Hilton, Life Coach
Association of Directors of Adult Social Services
Audrey Matthews, Chartered Clinical Psychologist
Body and Soul
British Association for Counselling and Psychotherapy
British HIV Association
British Federation against Sexually Transmitted Infections
British Medical Association Dermatology and Venereology Subcommittee
British Psychological Society Division of Health Psychology
Care Quality Commission
Chief Medical Officers' Expert Advisory Group on AIDS (EAGA)
Children's HIV Association (CHIVA)
Children and Young People HIV Network
College of Sexual and Relationship Therapy (formerly BASRT)
Darja Brandenburg, Consultant Clinical Psychologist
Dermatology and Venereology Subcommittee of CCSC, British Medical Association
Eileen Nixon, HIV Nurse Consultant
Ella Sherlock, Clinical Psychologist
Faculty of Sexual and Reproductive Healthcare of the RCOG
Feedback London (formerly Feedback South London)
Gordon Scott, Consultant in Genitourinary Medicine
Greater Manchester Sexual Health Network
Helen Griffiths, Associate Specialist in Allergy and Immunology
HIV Scotland
Institute of Psychosexual Medicine
Leicestershire AIDS Support Services
Mildmay UK
National AIDS Trust
Naz Project London
Paediatric HIV Psychology Group of CHIVA
Positive Action
Positive East
Positively UK
Rehabilitation and HIV Association (RHIVA)
Roshan das Nair, Consultant Clinical Psychologist (HIV & Sexual Health)
Royal College of General Practitioners (RCGP)
Royal College of Nursing
Royal College of Physicians
Royal College of Psychiatrists
Sex, Drugs & HIV Group of the RCGP
Sexual Advice Association (formerly Sexual Dysfunction Association)
Shika Tamaa Support Service
South West London HIV & GUM Clinical Services Network (SWAGNET)
Terrence Higgins Trust
Tomas Campbell, Head of Clinical Health Psychology, Newham Directorate, East London Foundation Trust
Waverley Care

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Standards for psychological support for adults living with HIV

Ensuring the psychological health and wellbeing of people with HIV is crucial both for individuals' quality of life, and for the benefits to public health that flow from reducing the burden of ill-health, increasing adherence to HIV treatment and reducing the risk of onward transmission of HIV. This in turn reduces costs to the public purse. Yet service provision varies widely across the country and those living with HIV may find themselves unable to access local services appropriate to their level of need.

These *Standards for psychological support for adults living with HIV* use a stepped care model for assessing and responding to varying levels of need for psychological support. A valuable tool for both providers and commissioners, they will serve as a lever to maintain high-quality services and care pathways where they exist, and to make the case for developing them where they do not.

The standards were developed by the Faculty for HIV & Sexual Health (FacHIV&SH) of the Division of Clinical Psychology of the British Psychological Society (BPS), the British HIV Association (BHIVA) and the Medical Foundation for AIDS & Sexual Health (MedFASH), with the active engagement of a multi-organisation and multi-professional working party.

About BPS, BHIVA, and MedFASH

Incorporated by Royal Charter, The British Psychological Society is the learned and professional body for psychologists in the UK. Its primary purpose is to advance and disseminate both pure and applied psychological knowledge. It also sets a high standard of professional education and knowledge for its members. Within the Society, the Faculty for HIV & Sexual Health promotes effective psychological services for people affected by HIV and other sexual health issues.

The British HIV Association (BHIVA) is the leading UK association representing professionals in HIV care. To secure the best possible care and outcomes for people living with HIV in the UK BHIVA produces nationally recognised guidelines, standards and audit programmes for HIV treatment and care.

The Medical Foundation for AIDS & Sexual Health (MedFASH) is a charity dedicated to the pursuit of excellence in the healthcare of people affected by HIV, sexually transmitted infections and related conditions. It has a track record of managing major national projects to inform policy development and provide practical guidance for professionals.

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