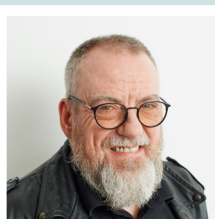
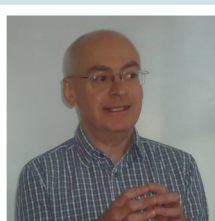
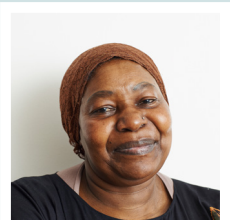
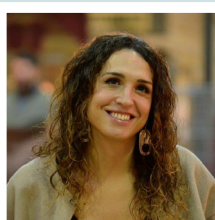
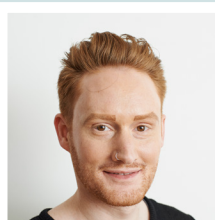


# Standards of Care

*for People Living with HIV* 2018





# British HIV Association *Standards of Care for People Living with HIV 2018*



## in partnership with

Association of Directors of Public Health (ADPH)  
British Association for Sexual Health and HIV (BASHH)  
British Infection Association (BIA)  
British Psychological Society (BPS)  
Children's HIV Association (CHIVA)  
Dietitians working in HIV/AIDS (DHIVA)  
HIV Pharmacy Association (HIVPA)  
National HIV Nurses Association (NHIVNA)  
Public Health England  
Rehabilitation in HIV Association (RHIVA)  
Royal College of General Practitioners (RCGP)  
Royal College of Physicians (RCP)  
Scottish HIV and AIDS Group (SHIVAG)  
Social Care Institute for Excellence (SCIE)

# British HIV Association

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

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# Foreword

This is the third set of quality standards for the care of people living with HIV in the UK. It has been produced by the British HIV Association (BHIVA), in partnership with care providers, professional associations, commissioners and people living with HIV. The Standards cover eight key themes that address the most important issues for the care of people living with HIV. They have been derived from the best available evidence, and focus on aspects of care that are particularly relevant to the delivery of equitable, high-quality services that secure the best possible outcomes for people living with HIV.

## Why has BHIVA developed these Standards?

Since the identification of HIV in 1983, there has been enormous progress in HIV treatment and care, with substantial improvements in both clinical outcomes and the lives of people living with HIV. Treatment outcomes for people living with HIV in the UK are among the best in the world and those who are diagnosed and treated promptly now have a similar life expectancy to the general population. At the same time, the increasing comorbidities of an ageing HIV population bring other challenges to the provision of excellent care. Recognition of the impact of effective virological suppression on transmission, alongside the emergence of other effective prevention interventions (e.g. pre-exposure prophylaxis [PrEP]) has resulted in improvements in sexual health and well-being as well as decreased transmission. The combination of the changing needs of patients and the current financial pressures make it very important that the care provided is both evidence based and value for money. The Standards provide a reference point against which to benchmark the quality of HIV care. Positioned alongside national and local policy and commissioning initiatives, we believe that the Standards will provide a framework to inform and support commissioning decisions both within and outside the NHS.

## Who is the intended audience for the Standards?

People living with HIV should expect to have equitable access to consistently high-quality care no matter where they live in the UK. The Standards will inform people living with HIV, their carers and those who advocate on their behalf about the care that people should expect to receive when they access HIV services. A user guide is being developed to accompany these Standards.

The Standards will be particularly relevant to anyone involved in the provision of services for people living with HIV, with clear information on what is required and why, together with ways of measuring and auditing performance.

Innovative and informed commissioning decisions are required to meet the growing need for more efficient and cost-effective services, and the Standards will be a critically important resource for those with responsibility for the commissioning of services affecting people living with HIV. The Standards will provide an important source of information for the policy and commissioning framework for HIV-related services at national and local levels, including the national HIV service specification and the payment-by-results system of currency and tariffs for HIV treatment and care.

## What do the Standards cover?

The Standards cover the range of care needed by people living with HIV from the time they first receive an HIV diagnosis. Standard 1 (Testing, diagnosis and prevention) promotes testing strategies that aim to reduce the proportion of people living with HIV who are unaware of their diagnosis or who present with advanced infection. It incorporates a section on the prevention of HIV.

Living well with HIV includes different aspects of well-being, dealing with HIV stigma, strong self-management skills, education and engagement in peer support, together with participation in decisions about all aspects of treatment and care, service design and delivery. Standard 2 (Person-centred care) focuses on these areas.

It is essential that people can access (and be retained in) specialist HIV care, as described in Standard 3 (HIV outpatient care and treatment). People living with HIV should also expect high-quality outpatient services and have confidence that appropriate systems are in place to ensure that antiretrovirals (ARVs) are prescribed and monitored safely (antiretroviral prescribing) wherever they live.

As people with HIV live longer, their health needs change, and both the numbers of comorbidities and the complexity of prescribing for multiple health conditions increase. Standard 4 (Complex HIV care) focuses on delivery of high-quality inpatient HIV services. It includes a separate section on comorbidities, co-infections and cancers, as well as highlighting the importance of supporting people with higher levels of need.

Standard 5 (Sexual and reproductive health) is about supporting people living with HIV to establish and maintain healthy sexual lives for themselves and their partners, highlighting the significance of virological suppression on transmission, and also covering the important and complex area of disclosure to, and testing for, potential contacts of infection. It aims to ensure high-quality reproductive and family health.

Living with HIV can take its toll on psychological and emotional well-being. Standard 6 (Psychological care) recognises the importance of providing care that promotes the mental, emotional and cognitive well-being of people living with HIV.

Standard 7 (HIV across the life course) recognises the diverse needs of people living with HIV at various stages in their lives; it brings together specific aspects of the standards that have particular relevance at different ages. It begins with young adults and adolescents, and spans young to middle adulthood and older age, in addition to highlighting the key issues for high-quality palliative care.

People living with HIV should expect to be treated by healthcare professionals who are up-to-date and fit to practise safely. Standard 8 (Developing and maintaining excellent care) sets out the competencies for a range of practitioners who may be involved with delivering care, and highlights the duty of all HIV services to maintain data security and contribute information to maximise understanding of the HIV epidemic in the UK.

Putting the needs of people living with HIV at the centre of service design and delivery will minimise morbidity and allow life to be lived to the full. Implementation of these Standards will be a major step towards achieving these aspirations for people living with HIV throughout the UK.

Fiona Burns, *Co-chair*  
David Chadwick, *Co-chair*  
Sheila Morris, *Co-chair*  
Ann Sullivan, *Co-chair*



# Acknowledgements

We are grateful for the support and guidance of all members of the Steering Group. Particular thanks go to those members who gave their time, energy and expertise to the drafting and redrafting of substantial sections of the document: Brian Angus, Vanessa Apea, David Asboe, Shema Doshi, Andrew Freedman, Jeffrey Grierson, Richard Harding, Alastair Hudson, Nicky Mackie, Alex Margetts, Iain Reeves, Karen Rogstad and Liat Sarner. Without their enthusiasm, dedication and expertise, this publication would not have been realised.

We are delighted that so many community groups contributed to the production of the Standards. The Writing Groups had representation from HIV i-Base, National AIDS Trust, North Yorkshire AIDS Action, Positively Mindful, Positively UK, Sahir House, Salamander Trust, Sophia Forum, The *People Living with HIV Stigma* Index UK, Waverley Care and UK-CAB. Community feedback on the public consultation draft was extremely helpful. More detailed information on contributions to the 2018 Standards is contained in Appendix 4.

We are very pleased that so many professional bodies, whose members have a role in providing HIV treatment and care to people living with HIV, were represented on the Standards Steering Group and Writing Groups and have agreed to endorse these Standards. The list of partner organisations and endorsements is shown at the front of this publication.

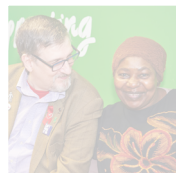
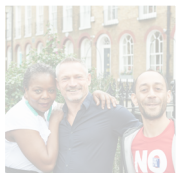
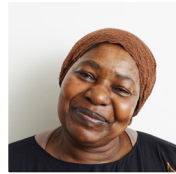
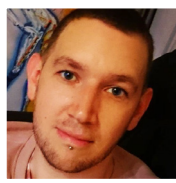
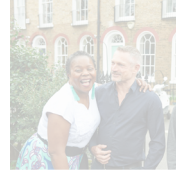
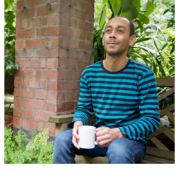
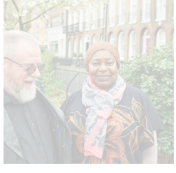
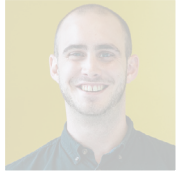
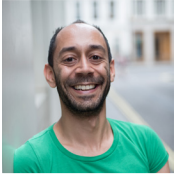
Thanks are due to all the individuals and organisations who took the time to respond to the online public consultation on the draft Standards and those who attended the stand at the BHIVA conferences in Liverpool and London to give useful feedback and advice. We are indebted to Hilary Curtis (on behalf of the BHIVA Audit and Standards Subcommittee) and the BHIVA Secretariat at Mediscript who provided expert technical and editorial support to the project team.

A special thanks to those living with HIV, those affected by HIV and those who may be at risk of acquiring HIV who volunteered their photos to illustrate these standards. It is the first time we have used 'real life' models and are extremely grateful to those who have contributed once more to the fight against the stigma associated with HIV. We are very grateful to Positively UK and UK-CAB for their help with organising this.

The entire project was made possible through grant funding from the MAC AIDS Fund, to whom we extend our particular thanks for their very generous support.

## BHIVA Standards of Care project team

**Alison Howarth**, *Project Coordinator*  
**Fiona Burns**, *Co-chair*  
**David Chadwick**, *Co-chair*  
**Sheila Morris**, *Co-chair*  
**Ann Sullivan**, *Co-chair*





# Introduction and background

## Introduction

HIV continues to be an important clinical and public health issue in the UK. Despite significant advances in antiretroviral treatment (ART) and consequent improvement in clinical outcomes, HIV remains a stigmatised and under-recognised condition that disproportionately affects already vulnerable populations. Gay and bisexual men, transgender woman, black African men and women, and people who use drugs continue to be disproportionately represented among people living with HIV. The biomedical, social, ethical and structural challenges associated with HIV all impact on the provision of care. The needs of people living with HIV, those affected by HIV and those at risk of acquiring HIV in the UK are particularly wide-ranging, cross many organisational boundaries and involve statutory and voluntary sectors within health and social care.

## Numbers and context

In 2015 it is estimated that 101,200 people were living with HIV in the UK, of whom an estimated 13% were unaware that they were HIV positive (PHE 2016). The majority (96%) of those attending HIV clinics were on ART and of these 94% had an undetectable viral load. There were 6095 people newly diagnosed with HIV, and 39% of these new diagnoses were made at a late stage of infection. Late diagnoses (CD4 count  $<350$  cells/mm<sup>3</sup> at the time of diagnosis) remained particularly high among heterosexual men (54%) and women (48%) compared to gay and bisexual men (30%).

Effective ART reduces morbidity and mortality and increases life expectancy, with the result that more people are living with HIV for longer, often with increasingly complex medical and social needs. In 2016, 91,987 people living with diagnosed HIV were being cared for by NHS HIV clinical services in the UK, a rise of 3% compared to 2015 (and 65% over the past 10 years), with very high levels of retention in care.

The rate of HIV transmission from mother to child was just under 0.3% for the 2580 births to women diagnosed with HIV in 2012-2014, continuing the decline from 0.46% in 2010-2011 and 2.1% in 2000-2001.

Despite these advances, late diagnosis of HIV continues to carry significant risks of morbidity and mortality, reduced life expectancy and increased rates of hospitalisation. Despite the move to a policy of early treatment for all, the definition of late diagnosis (CD4 count  $<350$  cells/mm<sup>3</sup>) is likely to remain pertinent, given its clinical correlation to risk of serious harm. Undiagnosed, untreated and the more-advanced stages of HIV facilitate onward transmission, compromising both individual well-being and the wider public health. Healthcare professionals in both primary and secondary care consistently miss and under-diagnose HIV, even in people who are symptomatic. Work funded by the Department of Health (between 2009 and 2010) has shown that broadening HIV testing and diagnosis throughout clinical and community environments in high-prevalence areas is both feasible and acceptable. Disappointingly these programmes have still not been widely implemented and embedded in routine care.

People with HIV are living into old age and older people are acquiring HIV, as they remain sexually active in later life. In 2016, more than one-third (38%) of adults accessing HIV care was over 50 years of age. Increased life expectancy results in an ageing HIV-positive population with above-average risk for cardiovascular, metabolic, bone and neurological problems, all of which are layered on top of an already complex medical condition. Chronic long-term condition management is becoming increasingly relevant to HIV care.

The combination of new HIV infections, increased life expectancy for people living with HIV, greater use of antiretroviral drugs and healthcare services, and changing comorbidities has increased HIV-related expenditure in the UK. The United Nations' goal of 90-90-90 (that by 2020, 90% of people living with HIV will be diagnosed, 90% of those diagnosed will be on antiretroviral treatment and 90% of those receiving antiretrovirals will be virally suppressed) has been achieved in London, although other parts of the country are still to achieve the first 90, albeit meeting the subsequent targets. HIV service delivery must evolve to meet the challenges of increasingly constrained resources and the varying needs of a changing population of people living with HIV. HIV treatment outcomes and retention-in-care rates are among the best in the world within the current models of care in the UK, and whatever service models are implemented, maintaining and improving these outcomes must remain the top priority for all those involved in the commissioning and delivery of care.

## Standards of care for people living with HIV in 2018

In 2007, BHIVA developed the first set of Standards for the clinical care of adults living with HIV, in collaboration with other stakeholders. The ensuing five years saw significant changes in the field of HIV as well as the commissioning and financial environment, resulting in the need for an updated version of the Standards, which was published in 2013. As the UK health and social arrangements continue to change, it is timely to update these Standards again, to include the latest recommendations for HIV care and ensure that they appropriately reflect the current needs of people living with HIV and remain relevant to all health services that provide HIV care.

In this document, we describe eight quality standards about the care that any adult living with HIV in the UK should expect to receive. Each standard presents a rationale, quality statements and measurable and auditable outcomes. Inclusion of outcomes does not imply that all of these should or will be audited; some may be best suited for national audit, but others are offered as suggestions for local or regional audit. The demography of HIV within the UK makes it very unlikely that there will be a 'one-size-fits-all' model of service delivery, and local arrangements and networks will be necessary to ensure that everyone living with HIV in the UK has equity of access to care that meets the appropriate standards. Clear care pathways into and through HIV services at local, regional and national levels are needed to

ensure that people living with HIV can access the care that they need. Many people living with HIV have particularly significant social care needs that may impact on clinical care and potentially compromise well-being. Therefore, an emphasis on integrated and collaborative care is essential if best outcomes are to be realised. Joined up commissioning across the local health economy will be key to achieving these standards.

## Scope of standards

We have developed standards of care for people living with HIV from acquisition, across the life course to end of life. Crucially, we include in this document people living with HIV who are as yet unaware of their HIV, as they are at significant risk of poorer health outcomes and inadvertent onward transmission. Testing for HIV is the key entry point for care, treatment and prevention services and is our starting point. The rate of new HIV infections in the UK remains high and the Standards emphasise the range of prevention options available, including the use of ARVs to reduce both HIV acquisition and transmission in the form of pre- and post-exposure prophylaxis (PrEP and PEP) and treatment as prevention (TasP), highlighting the pivotal role of people living with HIV in prevention efforts.

As the health and social care landscape evolves, care for people living with HIV will be delivered by a range of service providers, with greater and lesser HIV specialisation and experience. This document gives guidance to all providers on the appropriate standards of care for people living with HIV, the competencies required, and the expected quality outcomes. The Standards need to be read in their entirety and interpreted in light of each other.

Person-centred care is paramount if services are to provide care for people living with HIV which is relevant, appropriate and accessible. To ensure equitable and non-discriminatory care these Standards highlight the pivotal role of HIV-related stigma in all aspects of care, treatment and prevention. They include standards for enhancing self-management, well-being and ensuring meaningful user engagement in service design and delivery. They incorporate the appropriate care and services that people living with HIV should be able to access to enable physical, psychological, emotional and social well-being to enhance quality of life and promote best health outcomes. Including a specific standard on well-being makes clear the importance of these aspects of people's lives and highlights the contribution that care providers and people living with HIV can make to enhancing quality of life.

The Standards examine HIV across the life course, taking into account the key aspects of care for people at different stages of life, including young adults and adolescents, young to middle adulthood and older age. The optimisation of quality of life and relief of distress in serious, advanced illness is addressed under palliative care.

Maintaining and enhancing knowledge about HIV via both epidemiological/public health surveillance and research is a vital component of care and is included in this set of standards.

These Standards do not provide an exhaustive list but describe the minimum care that a person living with HIV should expect to be able to access. If services are to achieve these standards it will be necessary for providers to work collaboratively within network structures to ensure equity in access and provision for people living with HIV. It will also be dependent on all commissioners working collaboratively across the local health and social care economy, based on local needs assessments.

## Aims of the Standards

The aim of these Standards is to define a minimum standard of care that a person living with HIV should expect to receive. It is intended that implementation of these Standards will help those living with HIV to achieve the best possible health outcomes and live well with HIV.

### These Standards aim to inform:

- People living with HIV about the expected standards of their HIV-related healthcare, social care, support and well-being
- Service providers throughout the UK who are involved in any aspect of the delivery of healthcare to people living with HIV
- Commissioners who have responsibility for commissioning health and social care for people living with HIV

This set of Standards has been written in the knowledge of the existing Scottish National Involvement Standards (2017), the Psychological Standards for adults living with HIV (2011), and the National Standards for Peer Support in HIV (2017) and aims to complement these publications. Although only applicable to England, the Standards have also been reviewed to ensure that they are consistent with the delivery of the five domains of the NHS Outcomes Framework (2017) and are in keeping with the ambitions of the NHS Quality, Innovation, Productivity and Prevention (QIPP) agenda while sustaining high-quality care (see Appendix 5).

## Development of the Standards *(for additional details see Appendix 4)*

Input from a wide range of stakeholders has been sought to ensure that the Standards incorporate the key aspects of healthcare required to meet the needs of people living with HIV in the UK. The Standards reflect the views of people living with HIV, professional bodies, service providers, commissioners and advocacy groups. Although not intended to be an exhaustive list of all the aspects of care that a person living with HIV might need, the document seeks to set out those areas of care that are fundamental to high-quality outcomes.

The development of these Standards has included review and update of the 2013 Standards of Care; re-drafting of current standards and drafting new standards by Writing Groups led by a nationally recognised expert in the topic area; and consulting widely across all relevant stakeholders for feedback and comments.

## To whom do these standards apply?

Everybody living with HIV in the UK should have equitable access to uniformly high-quality HIV care. These Standards are applicable to all adults living with HIV in the UK, including people in places of incarceration such as prisons and immigration removal centres. HIV treatment and care in the UK is now exempt from overseas charging regulations.

## A population-focused approach for equitable access to and delivery of high-quality HIV care

Although the prevalence of HIV varies considerably across the UK, everybody living with HIV must have equitable access to high-quality treatment and care regardless of where they

live or which providers they use. Clinical safety and service sustainability is dependent on a critical mass of staff, expertise and resources. Collaborative working arrangements within, and between, HIV service providers are essential for both equitable delivery of care and for maximising efficiency.

In parts of the country with a low prevalence of HIV, collaboration is required to ensure that comprehensive, safe and sustainable specialist care is available to all people living with HIV in the area. Where HIV prevalence is higher, providers will need to collaborate to ensure that services are streamlined and efficient and that duplication is minimised.

No HIV service provider (large or small) should deliver services in isolation. HIV care for populations should be planned and delivered through networks. There is no single model for network design and commissioners will need to work with HIV and other health and social care providers, as well as service users, to identify how networks facilitate the delivery of effective and efficient care locally, regionally and nationally.

Networks should facilitate integration of care between different providers and commissioners. The development of appropriate measures and tools to evaluate the patient experience across whole journeys of care and to respond accordingly will be vital to ensure success of networks.

Once determined, networks of care should be formally defined, care pathways described and clearly communicated so that people living with HIV, referrers and providers are all clear on the roles and responsibilities within networked arrangements.

## Effective commissioning and delivery of healthcare for people living with HIV

Service provision needs to evolve in order to meet the changing needs of people living with HIV effectively and efficiently. Understanding the epidemiology of HIV across the UK is essential for service planning and delivery. Knowing how and why people living with HIV either do or do not use health and social care services is also required for effective service planning and commissioning to ensure optimal health outcomes.

### NHS England welcomes the work by BHIVA to update the standards, which will be taken into consideration when NHS England reviews its HIV service specification

**Rob Coster**, *National Programme of Care Manager, Blood and Infection, NHS England*

Medical and social care for people living with HIV is commissioned by a variety of organisations, both nationally and locally. Effective provision of care for people living with HIV depends on these organisations working together efficiently.

Concerns about confidentiality have limited the use of identifiable data in relation to HIV. Currently, data on the use of HIV-specific services in England, Northern Ireland and Wales is submitted by clinical providers to Public Health England with limited identifiers and is shared as anonymous data with commissioners.

## Language and terminology

The terminology used throughout this document is consistent with UNAIDS (2015) recommendations. Careful use of appropriate language, using terms that are clear and unambiguous, that put people first and that avoid perpetuating unhelpful stereotypes, is an important element of high-quality care.

References: 1–7

## Overarching principles

The BHIVA Standards of Care are to support people living with, or affected by, HIV in leading the fullest lives possible with the best attainable health. Certain overarching principles underpin all aspects of these Standards:

1. People living with HIV should be at the centre of their own care, with the ability to have meaningful involvement in the development and delivery of services.
2. There should be equality of access to, and equity in provision of, health and social care for all people regardless of age, gender, sexuality, ethnicity, religion, physical ability, health literacy, immigration or residency status. HIV remains a stigmatised and socially complex diagnosis that disproportionately affects already marginalised population groups. People living with HIV should be provided with equitable and non-discriminatory care across all health and social care settings.
3. All patient-related information whether clinical, pseudo-anonymised or anonymous should be held securely in compliance with information governance standards and national legislation. People living with HIV should expect that only data that are useful for surveillance, commissioning, monitoring of care or research will be collected and the information will not be used for any other purpose.





# 1. Testing, diagnosis and prevention

## 1a. Testing and diagnosis

*People attending healthcare services (primary, secondary and tertiary care) should be offered diagnostic tests for HIV in accordance with current national guidance.*

### Rationale

HIV testing and diagnosis are crucial in the response to the HIV epidemic, both globally and in the UK. In 2013, UNAIDS launched the 90:90:90 ambition, advocating that the epidemic can be reduced if 90% of people living with HIV know their status, 90% of those diagnosed receive treatment and 90% of those treated are virally suppressed. The UK exceeds the targets for access to treatment and viral suppression but is not yet achieving the target for diagnosis. The most recent national data estimates 13% of people living with HIV in the UK are unaware of their HIV status.

Timely diagnosis is also an ongoing challenge. In 2015, 39% of people who were newly diagnosed HIV positive in the UK were diagnosed late, increasing short- and long-term morbidity and mortality. Prompt HIV diagnosis also affords opportunities to reduce transmission of HIV to other people. Recognising primary HIV infection (PHI; recent HIV infection/seroconversion illness) is especially important due to high viraemia and, hence, risk of transmission. Assays used should be appropriate to capture all stages of HIV infection.

UK data from a wide range of clinical and community-based interventions have demonstrated that HIV testing is acceptable to patients, deliverable, cost-effective and saves lives. However, missed opportunities for early diagnosis of HIV in primary and secondary care continue to be well documented. Effective HIV testing strategies should be



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tailored to local populations and maximise the opportunity for testing in both non-clinical and clinical settings. Community testing initiatives have been found to be particularly effective among gay and bisexual men, and black African men and women. Sustainability of initiatives, such as opt-out testing, in wider medical settings will require local and or national policy (e.g. CQUINs, to incentivise all relevant stakeholders to embed HIV testing into their clinical pathways).

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Self-sampling and self-testing have emerged as acceptable and convenient methods for accessing an HIV test. There is an increasing number of providers of such testing kits, which requires tight regulation. Users should be reminded to check the test kit has met the appropriate regulatory requirements, has a CE mark and is clearly intended for self-sampling and self-testing.

There are significant personal and social consequences of an HIV-positive diagnosis that should be recognised in any setting where HIV testing is being carried out. Arrangements should be in place for confirmatory testing and linkage to specialist HIV care services for clinical, laboratory and psychosocial assessment so that an appropriate management plan can be developed. Best outcomes for people with HIV-related pathology depend on rapid recognition and appropriate intervention, and everyone should be seen for this specialist assessment within 2 weeks of receiving an HIV-positive diagnosis. People newly diagnosed with HIV who have symptoms and/or signs attributable to HIV (including those of primary infection) may need immediate intervention and so should be able to access urgent (within 24 hours) specialist assessment. Rapid assessment and intervention also has an important role to play in the prevention of onward transmission of HIV. Prompt involvement of an HIV specialist is particularly important if an HIV diagnosis is made during a hospital admission where HIV may be a significant causal factor.

People differ in their emotional and psychological reaction to a diagnosis of HIV and subsequent adjustment. Access to HIV-appropriate emotional, psychological and peer-support services is particularly important (see Standard 6). Peer support can improve people's knowledge, skills and confidence to manage their well-being and overall quality of life. It should be embedded in the clinical pathway to ensure everyone has access to peer support that is timely and meets the needs of the person, for example specific access to gay men's peer support, young adults, or peer support that takes account of spirituality and religious identity, with an initial appointment as soon as possible after diagnosis.

Implications of the diagnosis for others, particularly sexual partners and children, need to be explored with the patient thoroughly and sensitively, facilitating disclosure of the diagnosis to others and supporting people living with HIV through the process. This requires access to practitioners with skills in partner notification (PN) without delay following a diagnosis of HIV (see Standard 5a).

The need for testing the children of parents living with HIV, irrespective of their age and health status, has been highlighted in Don't Forget the Children. All new HIV-positive patients attending adult HIV services should have any children identified, tested or testing history obtained (and evidenced) and the information clearly documented. An illustration of how this can be approached when parents are reluctant is given in an appendix to the GMC guidance 'Protecting children and young people: the responsibilities of all doctors'. This can be a very worrying and stressful experience for both parents and children, and needs to be handled sensitively and supportively with a partnership approach, bearing in mind that the health of the child/children, who may have acquired HIV, is a priority.

## Quality statements

### Testing

- Routine offer of HIV testing should be made by competent healthcare professionals to all attendees in the following settings and clinical scenarios:
  - ◆ Contraceptive and sexual health services
  - ◆ Abortion services
  - ◆ Drug-dependency programmes including:
    - Injecting equipment providers, i.e. needle exchange services
    - Opiate replacement treatment services
  - ◆ Antenatal services
  - ◆ Services for TB, lymphoma and hepatitis B and C
  - ◆ All people with symptoms consistent with primary HIV infection
  - ◆ All people presenting with a clinical indicator condition specified in the UK National HIV Testing Guidelines
  - ◆ All people entering or transferring between prison services
  - ◆ All people at reception into immigration removal centres
- All those who present to medical and mental health services with identifiable risk factors (behavioural and geographical) should be offered an HIV test in accordance with national guidance.
- Annual testing should be offered to people in groups or communities with a high rate of HIV, and more frequently if they are at ongoing high risk of exposure (e.g. MSM and people who use drugs). MSM should have HIV and other sexually transmitted infection tests at least annually, and every 3 months if they are accessing PrEP and or having condomless anal sex with new or casual partners. People who use drugs should also have HIV tests at least annually, and every 3 months if they are currently sharing injecting equipment.
- In areas where the prevalence of diagnosed HIV is 2:1000 or greater, all adults admitted for secondary general medical care, including emergency departments, intensive care units and mental health services should have routine, opt-out HIV testing included in their initial health checks and medical work-up.
- In areas where the prevalence of diagnosed HIV is 2:1000 or greater, all adults registering with a general practice should have routine, opt-out HIV testing included in their initial health checks and medical work-up, and subsequently all those having a blood test at their general practice should be offered an HIV test if they have not had one within the last year.
- All local authorities' commissioning services should take into account the demographic of their local HIV epidemic in planning services, particularly ensuring that high-risk groups who do not routinely access NHS services have outreach and community-based services funded for testing appropriate for their needs.
- Where an HIV test has been recommended and declined, this should be recorded in the medical record. Reasons for declining a test should be explored. Written information about HIV testing and alternative testing options can be given to the patient and testing should be re-offered at the next earliest opportunity.

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- Point-of-care testing may be appropriate in a number of scenarios:
  - ◆ At community testing sites
  - ◆ In clinical settings where a rapid turnaround of test results is desirable
  - ◆ For urgent source testing (e.g. following a needlestick injury)
  - ◆ In situations where it would be difficult to give people their results (e.g. if they are unwilling to leave contact details)
  - ◆ If a person declines a venous blood sample
- At the time of a point-of-care test, people should be informed that confirmatory serological testing and contact information will be needed if the test is reactive.
- Self-sampling and self-testing kits should be offered as an additional approach to HIV-testing services. Validated tests should only be available with appropriate support and access to clinical care.
- When primary HIV infection is a potential diagnosis, diagnostic HIV assays that can simultaneously identify both antibodies to HIV and HIV p24 antigen (fourth-generation assays) should be used in addition to an HIV viral load.
- The time between performing an HIV test and the results being available to the patient should be reduced to a minimum, preferably within 48 hours, compatible with the assays available and the context in which the test is carried out.

## Children

- All children (defined as those who have not yet reached their 18th birthday) born to people living with HIV should be assessed for risks of vertical transmission.
- Testing children at risk of HIV acquisition should be discussed with at least one of the child's parents or legal guardians, and appropriate testing and follow-up organised with paediatric colleagues.

## Diagnosis

- Services that offer diagnostic testing for HIV should have an agreed pathway into specialist HIV care for people who are diagnosed HIV positive.
- People who have a new diagnosis of HIV should expect to have their HIV status fully assessed by appropriately trained staff within 2 weeks of receiving an HIV-positive test result (see Standard 8a).
- People who have a new diagnosis of HIV and have symptoms and/or signs potentially attributable to HIV (including those of primary infection) should be referred for urgent (within 24 hours) specialist assessment.
- People who receive their diagnosis within a hospital setting should expect to be reviewed by appropriately trained staff within 24 hours if their admission may be HIV-related, or within 2 weeks as an outpatient if unrelated to HIV (see Standard 8a).
- Partners of people who test positive should receive a prompt offer and recommendation of an HIV test through partner notification procedures.



## Measurable and auditable outcomes

- Proportion of people diagnosed late (CD4 count  $<350$  cells/mm<sup>3</sup>) or very late (CD4 count  $<200$  cells/mm<sup>3</sup> or an AIDS-defining event within 3 months of diagnosis), after excluding those with recent infection and a transient or early low CD4 cell count.
- Proportion of services undertaking a review of all patients diagnosed late (CD4 count  $<350$  cells/mm<sup>3</sup>) or very late (CD4 count  $<200$  cells/mm<sup>3</sup> or AIDS), with 'look back' of previous engagement with healthcare services (target: 95%). This critical case review should:
  - ◆ Be in line with the forthcoming national standardised process for reviewing late diagnoses (currently in development);
  - ◆ Include provision of summary information to commissioners to aid greater understanding of interventions to reduce late diagnosis.
- Proportion of people newly attending a sexual health service who have a documented offer of an HIV test (target: 90%). In other clinical settings, HIV testing should be offered in accordance with NICE guidelines and the testing rate should be measured.
- The proportion of HIV test results available to the requesting clinician within 5 working days, and accessible to the patient within 10 (both targets: 90%).
- Proportion of people with children with documented evidence that testing of children has been considered within 4 weeks of HIV diagnosis, irrespective of location of children (target: 95%), and that all children at risk currently in the UK have documented evidence of a test result within 6 months (target: 90%).

References: 1, 8-17

## 1b. Prevention

*All sexually active people should be made aware of, and have access to, a tailored and comprehensive package of HIV prevention options. This should include condoms, open access to free HIV and sexually transmitted infection (STI) screening, STI treatment, partner notification, behavioural interventions and the use of ARVs as post-and pre-exposure prophylaxis and treatment as prevention, where appropriate.*

### Rationale

HIV transmission is preventable; however, the rate of new HIV infections in the UK still remains high. A comprehensive, 'combination prevention' approach comprising a package of biomedical, behavioural and structural interventions, tailored to local populations, is the only effective way of tackling the spread of the epidemic. HIV prevention should go beyond primary prevention for HIV-negative people, and also work with people living with HIV as important partners in prevention. There is an ever-increasing array of evidence-based, HIV prevention tools available. These include condoms, STI screening and treatment, partner notification (see Standard 1a), motivational interviewing, peer support, comprehensive harm-reduction strategies (e.g. needle exchange programmes and opioid substitution therapy) and ARVs.

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Particularly notable in recent years is the use of ARVs by HIV-negative and -positive people to reduce HIV acquisition and transmission in the form of pre-exposure prophylaxis (PrEP) and treatment as prevention (TasP), respectively. The promotion of TasP has been strengthened recently by the production of an international consensus statement which, in summary, is that a person living with HIV who is on ART and has achieved an undetectable viral load in their blood for at least 6 months cannot transmit HIV to their sexual partners. All people living with HIV should be made aware of this (see Appendix 2).

**There should be no doubt that a person with sustained, undetectable levels of HIV in their blood cannot transmit HIV to their sexual partners**

*Chloe Orkin Chair, BHIVA*

PrEP consisting of oral tenofovir disoproxil fumarate-emtricitabine taken daily or on-demand prior to and following potential risk exposure is highly effective in preventing HIV infection. The PROUD and IPERGAY studies have provided strong evidence for a large reduction (>85% in both) in HIV incidence when PrEP is offered to MSM having condomless anal sex. Other groups have collected similar strong evidence for the benefits of PrEP in heterosexual men and women at risk of acquiring HIV. No single intervention has provided as dramatic a reduction in HIV transmission as PrEP. However, all studies have emphasised that PrEP should be delivered as part of a comprehensive package of HIV/STI prevention and targeted risk-reduction support.

At the time of writing, NHS access to PrEP is variable across the UK, with widespread accessibility only in Scotland and Wales. People in England currently have two options for accessing PrEP: either by purchasing PrEP from pharmacies selling generic products outside the European Union or from pharmacies within the UK with a private prescription, or by enrolling on the NHS England-funded Impact study (a pragmatic non-interventional study to determine need, uptake and use of PrEP when delivered in sexual health clinics). The Public Health Agency for Northern Ireland is reviewing PrEP provision and a report is expected in late 2018. In the interim, PrEP monitoring is being provided in some sexual health clinics. Primary care is not expected to issue PrEP but like other non-HIV and sexual health services, it can contribute to the broader HIV prevention strategy, for example HIV testing, provision of condoms, encouraging adherence to ART for those tested positive, and discussion about PrEP where available.

In 2017, at least five London sexual health clinics reported a dramatic reduction in the number of new HIV diagnoses over 2 years. This was thought to be primarily due to increased testing of the most high-risk people, earlier ART initiation (to effect TasP) and the increasing use of PrEP obtained privately and via research studies.

HIV transmission is a major concern for people living with HIV and their sexual partners. Awareness of the effectiveness of treatment is a powerful tool to support people living with HIV and a challenge to the stigma that they often face; all people living with HIV should be provided with this information and its implications.

We know there is a wide array of highly effective prevention interventions, we must now determine how best to deliver these. In an increasingly financially constrained environment, clinicians, community providers, patients and advocates should work collaboratively with commissioning bodies to design comprehensive prevention strategies to realise the full public health potential of all available prevention tools.

## Quality statements

- People at high risk of HIV acquisition (e.g. MSM, people who use drugs) and those living with HIV should be made aware of the range of interventions that has been shown to reduce the risk of HIV transmission, including the risks and benefits.
- An assessment of the risk of transmission to others should be made at HIV diagnosis and subsequent visits. People who are assessed as being at risk of transmission to others should be offered one-to-one risk reduction (see Standard 5a).
- HIV services should promote condom use as a safer-sex strategy and ensure that a range of condoms (male, female, various sizes and types) and lubricants is provided and available for people living with HIV.
- HIV services should raise awareness of the role of STIs in the context of HIV transmission and acquisition.
- People living with HIV should be made aware of the evidence that a person living with HIV, who is on ART and has achieved an undetectable viral load in their blood for at least 6 months cannot transmit HIV to their sexual partners.
- Pre-exposure prophylaxis (PrEP) should be considered in all HIV-negative people on a case-by-case basis, based on the BHIVA PrEP guidelines.
- PrEP should be delivered as part of a comprehensive package of HIV/STI prevention interventions, based on an individual's circumstances. These might include condoms and lubricant, safer-sex counselling, frequent STI check-ups and treatment, and regular HIV testing.

## Measurable and auditable outcomes

- Proportion of people with documented evidence of having had a discussion about HIV transmission and HIV prevention options (target: 90%).
- Proportion of people with sustained viral suppression (at least 6 months) and high adherence to ART with documented evidence that they have been advised that they cannot transmit HIV to their sexual partners (target: 90%).

**References:** 1, 18-26



## 2. Person- centred care

*Person-centred care means that services consciously adopt the perspectives of individuals, families and communities to respond to their needs and preferences in humane and holistic ways; the person is a participant, not just a beneficiary of the health system.*

Good-quality care should focus on the person and not only their illness. These Standards aim to ensure that care for people living with HIV is 'person-centred'. Person-centred care sees the person as an individual and considers their desires, values, family situations, social circumstances, and lifestyles. In so doing, needs and preferences can be responded to in humane and holistic ways, and people seeking care are seen as participants not just beneficiaries of the health system.

When people living with HIV are with healthcare professionals, it is important they are asked about their problems, symptoms and concerns. Despite ART, psychological and social problems persist, as does the experience of stigma. People living with HIV in the UK report a high burden of pain, other symptoms and psychological concerns, which are all associated with poorer adherence, suicidal ideation, poorer quality of life and treatment switching. People attending HIV care services in the UK have identified the need for health professionals to better identify and manage their physical and psychological concerns in order to achieve their life goals.

**References:** 27-38



## 2a. Stigma – equitable and non-discriminatory care

*All people living with HIV should be provided with equitable and non-discriminatory care across all healthcare settings including those outside sexual health and reproductive services.*

### Rationale

Stigma was originally conceptualised as the creation of a ‘spoiled identity’, which arises from the gap between how a person sees themselves and how they are seen by others. It is seen as a construct based on psychological, social and societal factors. It refers to an extreme disapproval of a person or group based on a characteristic that serves to distinguish them from other members of society. Fear of stigma and discrimination is a leading contributor to poor health outcomes for people living with or affected by HIV.

HIV-related stigma is widely reported and feared by people living with HIV, and refers to any form of prejudice, negative attitude, discrimination or abuse directed at people living with HIV because of their HIV status. This stigma may be in addition to pre-existing stigma based on actual or perceived membership of different social groups (e.g. gender identity, religion, age, class, ethnicity, sexuality).

The Equality Act applies in England, Scotland and Wales, and serves as protection against discrimination, across all health and social care settings. However, the findings of The People Living with HIV Stigma Survey UK 2015 show that in the preceding 12 months, one in seven (13%) reported hearing negative comments from a healthcare worker about themselves or other people living with HIV. The findings also show about one-third worried about being treated differently to other patients at their general or dental practice, and 5% felt treatment was refused or delayed across all healthcare settings because of their HIV status.

**As a woman living with HIV, I find that stigma and self stigma are sometimes more of an issue than the HIV itself.**

**Jo Josh, UK-CAB**

HIV-associated stigma has many negative effects on the lives of people living with HIV, undermining confidence and acting as a barrier to service uptake and utilisation. There is good evidence that stigma is associated with reduced engagement with healthcare services. People living with HIV will differ in their experience of stigma, historically, geographically and in relation to social context. Appropriate peer support enables people living with HIV to develop confidence and gain information and skills from others in an easily identifiable and applicable way, which is critically important for all other aspects of self-management.

It is critical to acknowledge that people living with HIV may also be faced with stigma based on other personal demographics that could be acting as compounding factors to their psychological well-being or health behaviours, in particular trans people and people who use drugs. For people who are engaging with services, care must be taken to consider the life stage they are in, which may influence their levels of resilience or stress.

All people using the NHS have the right to expect that their care is delivered in a safe environment, where they are treated with dignity and respect, and without fear of



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discrimination. Staff involved in delivery of outpatient HIV care should be mindful of the impact of HIV-related stigma and discrimination and able to support patients facing these issues, especially when this affects uptake or access to health and social care outside the HIV clinic

## Quality statements

- Staff across all health and social care services, including general practitioners and dentists, mental health, social care workers, employees of housing and support services, should receive basic information and training on blood-borne viruses (BBV) and access to resources on treating people living with HIV, including trans people and people who use drugs.
- Staff across all healthcare services should be provided with training on how to identify the impact and effects of stigma, including what it is, how it is manifested, the consequences on mental well-being and behaviour, as well as how issues can be addressed practically.
- Staff involved in HIV testing, diagnosis and treatment should have access to training and information that explicitly addresses the stigma and prejudice faced by people in key populations, in particular on the specific needs of trans people and people who use drugs, designed to challenge preconceptions and stigma still experienced by members of these groups.
- Healthcare services should ensure that staff members are aware of the confidential nature of people's medical records, including their HIV status.
- People living with HIV should be made aware of how they can raise concerns if they are unhappy with their care or have experienced stigma and should be supported in doing so. They should be reassured this will not affect access to or the standard of their care.

## Measurable and auditable outcomes

- Proportion of providers compliant with local organisational requirements for equality and diversity training.
- Proportion of providers with documented evidence of a patient experience survey in past 3 years to assess satisfaction with care across medical departments and monitor experience of stigma.

**References:** 39-43

## 2b. Self-management and peer support

*In keeping with the management of other long-term health conditions, people living with HIV should be enabled to optimise self-management and access peer-support opportunities to promote their physical and mental health, and overall well-being.*

### Rationale

Living with HIV requires lifelong adjustments and management. As with many other long-term conditions, self-management approaches can help people living with HIV gain confidence, skills and knowledge to manage their own health better, with resulting improvements in quality of life and independence.

It is important to recognise that the resources required to effectively self-manage will change across the life course. Self-management issues around key life phases and moments, (e.g. diagnosis, commencement of HIV treatment and care, entry and re-entry into the workforce, establishing relationships, sexual debut, pregnancy and having children, coping with loss, ageing, retirement, transitioning from paediatric to adult services will require different strategies and resources and have implications for different services). Access to material and social resources, including for basic needs, will have a significant impact on people's ability to engage with self-management.

UK health policy encourages an increased focus on self-management. Evidence shows that limited health literacy contributes to suboptimal care, poorer health status of affected people and avoidable costs within health systems. Across a number of long-term medical conditions effective self-management interventions have been shown to help build knowledge and skills among both individuals and groups of service users. Self-management and voluntary sector involvement in care also bring economic benefits to the community and to the health system.

Self-management involves people living with HIV developing an understanding of how their condition affects their lives and how to cope with the clinical, physical, psychological and social challenges it presents. Effective self-management allows people living with HIV to make the many daily decisions that improve their health-related behaviours and outcomes. Building capacity to optimally self-manage includes ways to manage current challenges and also preparedness for future challenges. It is in this area that strong networks of peer support can be particularly beneficial.

Peer support is a relationship in which participants see each other as equal partners and where the focus is on mutual learning and growth. Within NHS services, structured peer support is delivered by trained peer staff or volunteers, in both one-to-one and group settings. Trained peer supporters can model positive and health behaviour, and signpost to services and appropriate information. The focus is on strengths and abilities, motivating and working to achieve agreed goals and improve or maintain quality of life. Peer support is a key contributor to optimising self-management as it not only draws on community resources and expertise but allows people to contribute to communities.

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For people living with HIV, self-management can help with at least five interconnected major areas:

- Physical health, including HIV-specific issues, comorbidities that may be influenced by HIV, life-stage health issues (such as pregnancy, ageing, puberty), and general health matters
- Health promotion and prevention of ill-health
- Mental health and well-being, including resilience building and potentially reducing the development and/or exacerbation of emotional distress
- Economic inclusion and well-being, including access to financial and employment support
- Social inclusion and well-being (with peer support as a key intervention)

Self-management is an important part of comprehensive HIV care because:

- People living with HIV are best placed to know and understand their own needs;
- It allows people to take greater personal responsibility for their own health and well-being;
- Professional resources can be focused where they are most needed.

Services that provide care for people living with HIV should be delivered in a way that supports and facilitates self-management, and encourages staff to operate a strong self-management philosophy. This should include an assessment of individual needs, followed by assistance to access resources (including peer support, interventions and online resources) to develop confidence and competencies for living with HIV. Working with people living with HIV to identify their self-management needs, staff should be able to offer referral to a multidisciplinary range of services, professionals (including occupational therapists, physiotherapists, dietitians and speech and language therapists) and peer-support groups that will most effectively enhance their ability to self-manage. A variety of approaches can be used to help people access (and benefit from) self-management interventions, including telephone, one-to-one, group settings and online programmes.

Identifying ways to enhance service coordination and interdisciplinarity will play a critical part in making services accessible, appropriate and effective. It is important to ensure that models of care ensure equitable access to self-management support for people living with HIV regardless of personal characteristics (see Overarching principles).

## Quality statements

- People living with HIV should have equitable access to services that promote self-management of HIV including provision of support and information:
  - ◆ About HIV, treatment, healthy living with HIV, diet and lifestyle, and optimisation of general health including rehabilitation services
  - ◆ On maximisation of entitlement to health services and support
  - ◆ To enable people to optimise their entitlement and access to financial and housing support, and to optimise their ability to maintain/gain/regain employment
- HIV services should maximise the use of peer support as set out in the National Standards for Peer Support in HIV ([www.hivpeersupport.com](http://www.hivpeersupport.com)).



## Measurable and auditable outcomes

- Proportion of people reporting they feel supported to manage HIV (target: 90%).
- Proportion of services that provide, or have an agreed care pathway to, peer-support and self-management services (target: 95%).
- Proportion of services with agreed care pathways that include peer-support options (in-house and/or external agencies).

References: 44-47

## 2c. Participation of people living with HIV in their care

*People living with HIV should be actively involved in decisions about their own health and social care. People who use HIV clinical and support services should be actively involved in the design, planning, delivery and review of these services. Ensuring active engagement in decision-making may require support and resources for both people living with HIV and service providers.*

*Service providers should be able to demonstrate their commitment to participation through identification of strategies, pathways and resources for both individual engagement in decision-making and community engagement in service provision.*

### Rationale

#### Decisions about individual treatment and care

In line with provision of any care delivered by the NHS, people living with HIV should be as actively involved in decisions relating to their own care and treatment as they wish.

General Medical Council guidance sets out principles for good decision-making practice that apply to all decisions about care. Other professional regulatory bodies and national NHS guidance set out similar requirements. In summary, these state that people receiving care and health practitioners should work together to make informed decisions about treatment and care. People living with HIV can expect:

- To be listened to and have their views about their health respected
- To be actively engaged in discussions about their diagnosis, prognosis, treatment and care
- To have access to information they want or need, in a way they can understand in appropriate formats, in order to make decisions
- To be provided with opportunities and supported to make decisions for themselves
- To have their decisions respected, including the right to stop or refuse treatment
- To be provided with the resources and support to build their confidence and skills in joint decision-making

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Trust and good communication between the person receiving care and the healthcare practitioner lead to better adherence and outcomes. A range of information resources and support services is available to help. Information can include printed, online information, telephone advice lines, with support services including treatment advocates and one-to-one and group peer support. These all complement clinical services and are helpful in addressing the following factors that may have an impact on achieving good outcomes:

- Physical and psychological readiness for treatment
- Understanding how ART works, its efficacy and how this is measured
- Concerns about taking ART or using specific ARV drugs, including potential or actual adverse effects
- Concerns with possible adverse social consequences of actions such as talking to others about HIV
- Confidence in the ability to adhere to ART and the importance of adherence
- Psychological or cognitive issues that could have an impact on adherence (e.g. depression, memory problems, drug or alcohol use)
- Issues related to living long term with HIV and ageing with HIV and the impact these might have on treatment and health management
- Understanding of other treatments and medications, particularly in how these may interact with HIV and ART
- Socio-economic, cultural or practical factors that could have an impact on adherence, (e.g. income, housing, faith, intimate partner violence, abuse, stigma and acceptance of their condition)
- Confidence in talking to medical staff about HIV and other health issues
- Accessing primary care services, particularly GPs, to manage other health concerns
- Managing care plans across multiple long-term conditions and multiple treatment regimes
- Engaging with palliative care services and actively participating in decisions about palliative care.

Involving people living with HIV in their healthcare supports long-term, chronic condition self-management (see Standard 2b). The experiences of people receiving healthcare are important measures of service quality.

Not all populations of people living with HIV have the same personal or structural capacity to engage effectively in shared decision-making about their care. Specifically people who use drugs, those with liminal migration status and those facing communication challenges may be less able to engage in these processes. Particular attention needs to be paid to the structural disadvantage that this may entail.

### Planning services

Participation of people living with HIV in service design, planning delivery and review allows providers to both understand and meet the needs of the communities served.

As an activist, contributor and beneficiary of these standards it has been greatly encouraging to see BHIVA walk their talk by 'meaningfully' engaging community members at every stage in the development and production of this resource.

Alastair Hudson, *The People Living with HIV Stigma Index UK/FPA*

People living with HIV have consistently advocated for participation in decision-making about services they use and for people living with HIV to be treated with dignity and respect, to which the design, delivery and performance of clinical services contribute. The right to be consulted on healthcare is enshrined in law and clarified in NHS guidance. Attention needs to be paid to the diversity of experience among people living with HIV to ensure that this is reflected in practice.

Services need to build in adequate time for patient consultation and include training and capacity building that allows patients to understand their services, their place within NHS structures and the role of patients and communities in contributing to service planning. While HIV treatment and care are provided within the NHS, depending on where you live, sexual and reproductive health services and community support services may reside within local authorities and patients need to understand who is responsible for different aspects of their care in order to engage effectively. The community and voluntary sector can be engaged to support this.

Ultimately, management of HIV is likely to require greater involvement from primary care/ GP services as is the case with other long-term conditions such as diabetes, chronic lung disease, and heart failure.

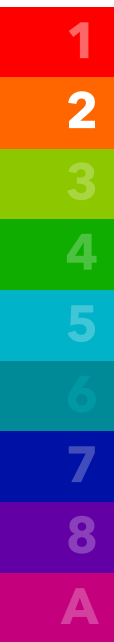
Practitioners and managers will need to acquire, and be supported to acquire, the skills and resources needed for fruitful engagement and consultation.

## Quality statements

### Decisions about individual treatment and care

- Services should place the patient at the centre of decision-making and ensure that assessment and delivery of care addresses both clinical and patient-reported outcomes and priorities.
- Services should ensure that decisions made together by people living with HIV and practitioners follow national guidance and professional standards for shared decision-making in all aspects of care.
- Services should ensure that people living with HIV have access to written information about investigations, ART and other aspects of their HIV treatment and care, or are able to provide the equivalent orally if this is preferred or necessary. At a minimum, services should ensure access to written information about:
  - ◆ The purposes and methods of monitoring CD4 count and viral load, the frequency, and what these tests mean
  - ◆ How ART works, including the importance of adherence and the risks and benefits of treatment





- ◆ The choices for ART, including potential side effects from individual drugs and how these will be managed if they occur
- ◆ Information about the importance of drug interactions, particularly in relation to comorbidities and other long-term conditions
- ◆ Information about improving general health outcomes
- People living with HIV should expect information to be available in a language that is understandable and in a format relevant to individual needs, including age and literacy level.
- Developing capability for shared decision-making should be encouraged and facilitated in clinicians, people living with HIV and the community sector, in particular for those whose background circumstances may compromise their full participation in evaluating options for treatment and care.
- Developing capability for shared decision-making should recognise the structural disadvantages experienced by some groups of people living with HIV (e.g. people who use drugs, those with uncertain migration status or those with communication challenges). Developing tools to address this disadvantage should be a priority for services providers.

### Planning services

- To ensure that services are fit for purpose and responsive to users' needs, opportunities (formal and informal) should be available for people living with HIV, individually or through the community sector, to be involved in service design, planning, delivery and review. Opportunities for service-user involvement should be multiple, varied and widely publicised.
- People living with HIV should expect to be able to provide feedback, ranging from comment on individual consultations to involvement in service commissioning, as well as the chance to give named and anonymous input into service design, delivery and performance review at local, regional and national level. Their involvement should remain incorporated in national guidelines.
- Information related to consultations about service planning and delivery should be published in appropriate physical (e.g. public notice boards) and virtual (e.g. service provider's web site) locations.
- Formal structures for service design and review should always factor in adequate time for meaningful service-user input and include community representatives who should, as far as is practical, reflect the diversity of the population served. There should be transparent mechanisms for selection of community representatives and for the wider involvement of people living with HIV in these structures.
- Practitioners and managers within HIV services should be supported to acquire the skills and resources needed for genuine and meaningful engagement and consultation with service users. There should be due recognition that people living with HIV are also part of the clinical, social care and service workforce.



## Measurable and auditable outcomes

### Decisions about treatment and care

- Proportion of people who report being satisfied with decisions about their care (target: 80%).
- Proportion of people with documented evidence that they have either received written information about their ART, including details for each drug prescribed, or have been given equivalent oral information if they prefer this option (target: 90% of total people on treatment).
- Proportion of people who confirm they have been involved in making decisions about their care (target: 90%).

### Planning services

- Proportion of people living with HIV participating in service planning and consultation who are satisfied with the opportunities for their involvement (target: 80% of total people participating).
- Proportion of services with evidence of routine participation of people living with HIV, as individuals or through representatives, in service design, planning, delivery and review.

References: 1, 48-53

## 2d. Well-being

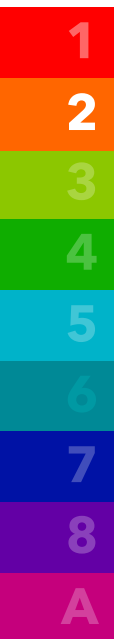
*Well-being is specifically that aspect of health that is concerned with the psychological, social and physical resources an individual can draw on to meet their life challenges and to increase their happiness and quality of life. People living with HIV should receive care that takes account of and enhances their well-being beyond their physical health and life expectancy.*

### Rationale

Well-being in the context of these Standards is a consideration of the broader quality of life issues for people living with HIV beyond treatment of the virus and beyond physical health and increased longevity. While there are clear intersections between well-being and mental health, the emphasis here is on the more holistic sense of self-worth and happiness that contributes to quality of life for individuals and communities. The aim of quality health and social care is to create lives that are worth living. While this includes many factors that are beyond the remit of these Standards, there are key contributions that service providers have and can continue to make to the well-being of individuals and communities of people living with HIV more generally.

Improving and maintaining well-being for people living with HIV clearly brings individual benefits, including greater happiness, social participation, self-worth, improved physical health, greater resilience in the face of adverse events, and more opportunities to contribute to society.





The broader community benefits of increased well-being include the greater participation of people living with HIV in society, reductions in community stigma, lower community viral load and consequent onward infection. The highly visible HIV partnership approach and emphasis on holistic well-being has provided a key model for other areas of the health service.

While the benefits of improving and maintaining well-being may be self-evident, the practices, policies and actions that enhance well-being are often overlooked or undervalued in service provision and assessment. These practices can include: the consideration of social and psychological contexts in the provision of care; the establishment and maintenance of strong professional networks that facilitate continuity of care and efficient referral; productive engagement with community sector organisations to ensure continuing relevance; and public advocacy in partnership with communities to ensure continued best-practice service provision. These are all things that have characterised the HIV service sector historically and contribute directly to the well-being of people living with HIV and their communities.

The increased emphasis of person-centred care is particularly useful in promoting models of well-being that are appropriate to people's life circumstances and values. The NHS person-centred skills and education framework provides a useful tool for services to undertake self-assessment in this area.

Agencies providing HIV care have a responsibility to ensure that well-being is an issue that is considered in the design, review and provision of services and there are opportunities for referral and support that enhance well-being. Attention to and responding to issues such as homelessness, immigration experience, access to education, intimate partner and gender-based violence, drug and alcohol use, stigma and social exclusion within the remit of the service will assist in optimising life outcomes for people living with HIV.

Feedback and input should be sought from people living with HIV and the community sector on the contribution of services to the well-being of people living with HIV and their communities. It is critical that this feedback, particularly the positive aspects of it, reach service providers.

## Quality statements

Services should ensure that:

- Issues of well-being continue to be incorporated into clinical and care practices in transparent ways
- A person-centred approach is taken in providing care to ensure that well-being for each person is holistic and meaningful
- Well-being is a consideration when developing, delivering and assessing services and policies in health and social care for people living with HIV
- Pressure on the cost and time available to provide clinical services does not result in the erosion of well-being initiatives or considerations
- Best practice service provision that incorporates concerns of individual and community well-being should be broadly communicated

## Measurable and auditable outcomes

Within HIV care:

- Documented evidence of a local guideline for assessment for and access to support around accessing benefits and financial hardship.
- Proportion of people in whom patient-reported outcome measure (PROM) is used to identify symptoms, concerns, priorities and outcomes of care (target: 90% of those with capacity to participate) (BHIVA PROMs in development at time of publication).
- Documented evidence of the use of patient-reported experience measure (PREM) to assess patient experience in past 3 years (target: 95% of services) (BHIVA PREMs in development at time of publication).

**References:** 44, 54-61





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## 3. HIV outpatient care and treatment

### 3a. Access to and retention in care

*People newly diagnosed with HIV, wherever they are tested, should be offered a full assessment, carried out by an appropriately trained practitioner with specialist expertise in HIV, at the earliest possible opportunity and no later than 2 weeks after receiving a positive HIV test result.*

*Services should have mechanisms in place to ensure all people living with HIV are retained in specialist care.*

#### Rationale

The HIV care continuum describes HIV care as a progression from testing to HIV diagnosis and linkage into care, retention in care, adherence to ART, and, ultimately, suppression of the virus. In practice, an individual does not simply move sequentially through each stage of this continuum. Engagement in care is dynamic and disengagement from care may happen at any time. The prognosis for people living with HIV who engage fully with specialist HIV care with high-quality, tailored multidisciplinary management continues to improve, with ongoing reduction in morbidity and mortality.

HIV remains a stigmatised and socially complex diagnosis that disproportionately affects already marginalised population groups. People living with HIV should be able to access appropriate specialist HIV care without fear of discrimination. Specialist HIV services should be provided in a non-judgemental environment in which people living with HIV feel secure and where their confidentiality and autonomy is actively respected. People living with HIV who are less well engaged in care have a significantly increased risk of mortality.

Systematic monitoring of engagement in care and mechanisms to identify and follow up those that do not attend (DNAs) is imperative for a high-quality HIV service. There is currently no gold standard for measuring engagement in care. The approach taken by the NHS England HIV quality dashboard includes indicators for the proportion of patients who re-attend during the 12-24 months after HIV diagnosis and after being seen for care. It is valuable to review these as a measure of performance, but individual patient management procedures are needed to recognise and respond to signs of disengagement before the 24-month indicator cut-off is reached.

People may become disengaged from specialist HIV care at various points along the care continuum for a variety of reasons. It is important to recognise these reasons may relate to individual, community and/or structural issues. Services should be designed and delivered in ways that maximise the opportunities for people living with HIV to consistently attend and remain engaged in care. At the time of re-engagement, it is essential to try and understand the reasons that led to the individual's disengagement, and where possible to address these with tailored interventions. This might mean, for example, increasing the offer of evening appointments.

Recent data highlight factors that may be predictive of suboptimal engagement in care in newly diagnosed people. These include age at diagnosis, having children, recreational drug use, drug/alcohol dependency, insufficient money for basic needs and use of public transport to get to the clinic. People with mental health comorbidities and people who use drugs may also be at particular risk (see Standard 4c). Close working links between primary care, secondary care, mental health services, social care, legal services, benefit agencies, peer support and voluntary sector agencies is required in these situations to maximise well-being.

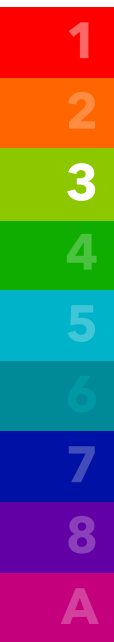
People living with HIV may relocate, be detained or incarcerated, or choose to engage with a new HIV service. Mechanisms should be in place for seamless transfer of care, both from the sending and receiving clinical services, with appropriate transfer of information between teams.

Increasing numbers of children living with HIV in the UK are entering adolescence. The process of adolescents successfully making the transition to adult HIV services is complex and should be managed by a multidisciplinary team in accordance with CHIVA guidance.

## Quality statements

### Access

- People newly diagnosed with HIV should have the initial investigations and assessments recommended in BHIVA guidelines and be able to access psychological and peer support within 2 weeks of receiving their HIV positive result.
- People newly diagnosed with HIV should be informed of their CD4 count and have the opportunity to discuss management, starting ART and opportunistic infection prophylaxis (if indicated) within 2 weeks of this initial assessment (i.e. within 1 month of initial diagnosis).
- People living with HIV should expect to have access to appropriately trained HIV specialist professionals for opportunities to discuss emotional, psychosocial and partner notification issues, as well as access to community support, especially when newly diagnosed with HIV (see Standard 8a).



- HIV outpatient units should have an agreed pathway to enable access to peer support.
- HIV outpatient units should have an agreed pathway to enable access to financial and housing advice and support.

### Retention

- HIV services should have mechanisms to identify and follow up people registered with their service, who become disengaged from care, who miss appointments or run low on medication.
- HIV services should have mechanisms in place to explore the reasons for disengagement when people living with HIV re-engage with services and where possible address identified reasons for disengagement.
- People living with HIV should expect to have access to peer and psychological support when required, particularly when facing a significant life event such as starting/changing treatment, major illness, pregnancy and menopause.
- If a patient is dissatisfied with the care provided by an individual clinician, an alternative should be offered (including referral to another centre if necessary or the dissatisfaction is with the service in general) after exploration of the basis for concerns and addressing as appropriate.
- HIV services should have agreed processes for the safe transfer of care, both from the sending and receiving clinical services, with timely transfer of appropriate information between teams.
  - ◆ Patients who transfer their care to another centre should have a full clinical summary provided from their former to their new treatment centre within 2 weeks of this being received by their former centre of care. This summary should contain, as a minimum, the information outlined in the BHIVA investigation and monitoring guidelines.
  - ◆ The transferring centre should ensure the provision of adequate medication to cover the transfer period.

### Measurable and auditable outcomes

- Proportion of people newly diagnosed with HIV who have a CD4 count result in their clinical record within 1 month of their HIV diagnosis (target: 95%).
- Proportion of people newly diagnosed in primary and secondary care and community settings, who are offered an appointment at an HIV specialist department within 2 weeks of diagnosis (target: >90%).
- Proportion of people newly diagnosed with HIV who are offered referral for peer support (target: 90%).
- Proportion of newly diagnosed adults (who have not died or transferred their care) retained in care in the year following diagnosis (target >90%).
- Proportion of people who attended an HIV service in the previous 12-24 months who are not known to have transferred their care or died, who have accessed HIV clinical services within the past 12 months (target: 90%).
- Proportion of people who have not transferred their care or died, who have not accessed HIV clinical services within the past 12 months in whom there is documented evidence of efforts to re-engage them (target: 95%).

References: 6, 48, 62-64

## 3b. Outpatient care

*People living with HIV attending an outpatient HIV service should have their HIV monitored and treated safely in accordance with national guidance.*

### Rationale

Outpatient care for people living with HIV should be person-centred and follow current national guidelines for support, monitoring and treatment to maximise the benefits of ART, to allow early detection of treatment- and HIV-related complications and to promote a good quality of life.

As increasing numbers of people live with HIV, services should facilitate living well with HIV by working within the local health and social care system, and engaging particularly with other sectors such as primary care. There is an established relationship between HIV and an increased risk of other health problems, ranging from some cancers through to mental health and sexual health. In these, as well as other areas such as pregnancy, there are specific HIV-related issues ranging from medical management through to the patient's experience of stigma and difficulties in communication with partners and family. The interfaces between HIV care and other health and social care services are particularly important and should be as smooth and seamless as possible.

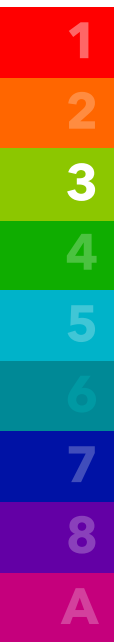
People living with HIV who have complex care needs should have their care delivered in settings with the appropriate range of specialist knowledge, skills and services and there should be local arrangements, such as care pathways, to allow equity of access to this expertise. 'Virtual' arrangements, such as access to specialist advice via email or by phone, should be used where direct contact is not feasible. On the other hand, people living with HIV who are well and do not currently have significant health-related needs may also appreciate virtual care arrangements in order to minimise the requirement for time spent attending clinics.

Access to important aspects of healthcare is best achieved through primary care, particularly as patients age and become more likely to develop comorbidities. Services should communicate well with other specialties and primary care with respect to HIV, specific comorbidities and drug-drug interactions. There should be clear protocols and pathways for care across the primary and secondary sectors to maximise patient safety and clinical effectiveness. Regular communication between these services should take place, unless the patient specifically withholds consent. When patients withhold consent, HIV services have a responsibility to understand, explore and discuss any concerns, while primary care services have a duty to ensure that all clinical and non-clinical staff understand the particular issues experienced by people living with HIV with respect to stigma and discrimination.

### Quality statements

- People living with HIV attending specialist HIV outpatient services should receive care that follows national guidelines for the diagnosis, treatment and monitoring of HIV and its complications.
- People living with HIV should receive care in appropriate designated facilities that guarantee privacy and confidentiality.





- Specialist HIV outpatient services should provide easy access to multidisciplinary support, in particular: specialist nursing; sexual health services; specialist adherence support; specialist HIV pharmacy advice; dispensing services; dietetics; mental healthcare; counselling; and peer and advocacy support. There should be ready access to, or information about, services that can provide advice about social care and benefits entitlements.
- The standard of care delivered to people living with HIV should be the same, whatever their circumstances. People in prisons or in other closed settings, such as detention centres have the right to the same quality of care as other people living with HIV. Services should seek to provide flexible care arrangements for particularly vulnerable people (e.g. homeless people and people who use drugs).
- People living with HIV should have ready access to health promotion and screening services as for the general population, but providers must recognise and act where more frequent screening is recommended in national guidelines.
- People living with HIV should have access to services to safely manage comorbidities, in collaboration with primary care and/or the appropriate non-HIV specialist team. Services should seek to agree local arrangements for the management of comorbidities where the roles and responsibilities of different agencies are clear, and lines of communication are robust. Clear, agreed pathways should exist for entry into more specialist services where people have less common or more complex problems.
- Services providing HIV outpatient treatment and care should have a designated HIV inpatient unit(s) to which patients requiring admission to hospital with serious HIV-related pathology can be referred and where advice can be obtained 24/7.
- Where antiretroviral treatment choice is affected by resistance, drug interactions or comorbidities, this should be recognised and discussed at the appropriate specialist level, including representation from the relevant professional disciplines as specified in national guidelines. These arrangements may be physical or virtual.
- There should be evidence that patients have been offered a copy of letters and that this was sent to those who wish it.

## Measurable and auditable outcomes

- Proportion of newly diagnosed patients with documented evidence of a clinical assessment and who are offered the opportunity of starting antiretroviral treatment according to BHIVA guidelines (both targets: 90%).
- Proportion of patients with documented evidence that the results of HIV viral load, CD4 count, HIV resistance assay, HLA-B5701, and tropism tests were available within 2 weeks of specimen collection (target: 90%).
- Proportion of services with agreed care pathways for integrated care or for referral of patients with conditions requiring specialist input, such as hepatitis co-infection, TB or treatment-related end-organ damage (target: 95%).
- Proportion of people who are medically stable with evidence of communication with GPs in the previous 15 months for those who have consented to share information with their GP (target: 95%).
- Proportion of people who present with new health problems or have a change in ART with evidence of communication with GPs after each medical appointment (target: 95%).

References: 6, 11, 24, 65-72



## 3c. Antiretroviral prescribing

*People living with HIV should be prescribed antiretroviral drugs by an appropriately qualified clinician and receive treatment with such drugs and monitoring that follow current national guidance*

### Rationale

Antiretroviral treatment (ART) suppresses viral replication at various stages in the viral lifecycle, but does not eliminate HIV and therefore treatment is lifelong. The pharmacokinetics and pharmacodynamics of these agents and their interactions with other medicines can be complex. HIV treatment regimens should meet the particular requirements of individual patients.

Choices about starting and changing ART, and which drugs to use, require prescribers to possess and integrate data on the interpretation of the genetic make-up of both the virus and the host, while at the same time assessing the ways in which antiretroviral pharmacology and drug interactions may impact on pre-existing conditions. Safe and effective prescribing of appropriate ART is crucial to maximise benefits, minimise adverse effects, avoid drug interactions and reduce the emergence of drug resistance. Good communication with well-informed and supported patients who participate in shared decision-making about treatments is an essential component of success.

Prescribing of ART should be supported by safe and effective use of clinical and laboratory monitoring of drug response, drug toxicity and treatment adherence. There is evidence that a substantial proportion of people prescribed ART are at risk of a clinically significant drug-drug interaction and this risk may increase as people age and are likely to be prescribed more drugs by different prescribers. Safeguards must be in place to minimise errors and promote good prescribing.

Robust engagement with primary care to minimise potential drug interactions is an essential aspect of good prescribing practice. Polypharmacy is increasingly recognised as an important factor in patient safety and a number of resources exist to guide healthcare professionals and patients. Recommendations from these resources inform, and are incorporated into, our quality statements below.

ART continues to represent a major component of the costs of treatment and care for people living with HIV in the UK; this means that clinically effective and cost-effective prescribing is essential to make efficient use of NHS resources. As generically manufactured antiretrovirals become increasingly available, treatment changes for reasons of cost saving are more frequent. Informed decision-making with the patient having a sense of control in this process is likely to increase the success of this strategy. The development of drug resistance and toxicity through inappropriate HIV prescribing might further increase costs so careful consideration of patient engagement and switch choice is important. Patient information and resources about generic medications are available from professional and third sector organisations.



## Quality statements

- ART should only be prescribed by an appropriately qualified practitioner (see Standard 8a).
- ART should be prescribed in line with national guidance and best available evidence, in partnership with each patient, taking into account their wishes and concerns to inform shared decision-making.
- People living with HIV should have access to adherence support, which should be provided by staff with appropriate skills, when starting or switching ARVs and at any time when viral rebound or suspected low adherence occurs. There should be evidence of adherence assessment as per national guidelines. Any patient reporting missed medication or experiencing viral load rebound should receive adherence support, noting the evidence of the contribution of psychosocial factors to adherence and the potential benefit of peer support.
- Information relating to past ART prescribed should be recorded in the patient's clinical records. This information, including reasons for previous treatment changes should be as accurate as possible. When patients transfer into the service, there should be evidence of an attempt to obtain this information from the previous care provider as well as baseline and any further resistance tests.
- A drug history should be undertaken and documented each time ART is prescribed by either the prescriber or an HIV specialist pharmacist. Clinical records should include details of all prescribed medication from primary care, the HIV service, any other specialist service, over-the-counter medication, herbal medication and recreational drugs, with an assessment for drug-drug interactions.
- Prescribers of ART should be able to readily access and use web-based information and decision-support tools to support best prescribing practice, and to help reduce medication errors. Patients should be encouraged to access the same or similar tools to be able to check and monitor their own medications.
- Antiretroviral prescriptions should be clinically verified by an HIV specialist or an adequately trained pharmacist, prior to dispensing, with respect to appropriateness with other prescribed medication and comorbidities.
- Mechanisms should be in place to alert primary care to potential drug-drug interactions and for primary care to verify non-HIV-related prescriptions issued to people living with HIV.
- HIV services should provide pharmacist- and nurse-led interventions, including outreach in the local community, to provide flexible care arrangements supporting ART prescribing for patients who have difficulty attending clinic appointments.
- People in prisons or other detention facilities should have a regular and continuous supply of ARVs alongside adequate access to an HIV specialist, and continuity of both treatment and access should be maintained when being moved between facilities. On leaving these facilities they should be provided with at least 1 month's supply of medication to allow continued adherence while making their own arrangements for a further supply and a booked follow-up appointment with an HIV provider.
- HIV services and patient representatives should work in partnership with commissioners/health boards to develop strategies to maintain cost-effective prescribing.
- HIV services have a duty to participate in regular monitoring of efficacy and safety of ARV prescribing locally, regionally and nationally.

## Measurable and auditable outcomes

- Proportion of people with documented evidence of a discussion about ART adherence within the first 3 months of starting ART and at least annually thereafter (both targets: 90%).
- Proportion of people who have a documented medication review in the past 15 months (target: 90% of patients attending).
- Proportion of people with documented evidence of being offered written information and access to peer support when making treatment decisions and in reporting side effects (target: 90%).
- Proportion of people on ART who experience viral rebound who were previously suppressed or where viral suppression is not achieved after treatment initiation who are managed according to national guidelines (target: 90% of patients meeting these criteria).

References: 6, 24, 48, 73-81





## 4. Complex HIV care

### 4a. Inpatient care

*People with proven or suspected complications of HIV or its treatment who require admission to hospital should receive equitable and rapid access to care by appropriately trained staff either within a consultant-led HIV specialist multidisciplinary team or, when not feasible, within an acute medical team supported by immediate and continued engagement with specialist HIV expertise and advice.*

#### Rationale

HIV-positive people presenting with complications of HIV can be critically ill with life-threatening conditions and require complex care including intensive care. Management for these patients should be provided by an HIV specialist consultant-led multidisciplinary team, frequently in collaboration with other medical specialties. According to Public Health England of the 6095 people diagnosed with HIV in 2015, 39% were diagnosed at a late stage of the infection. People diagnosed late are at increased risk of developing an AIDS-defining illness and continue to have a ten-fold increased risk of death in the year following their diagnosis, as compared with those diagnosed promptly (31.5 per 1000 compared to 3.6 per 1000). One-year mortality was particularly marked among people aged 50 years and over, where one in 16 diagnosed late died within a year of diagnosis. If appropriately managed, people presenting with severe HIV-related complications should expect a good long-term prognosis. Best clinical practice for the management and treatment of HIV-associated opportunistic infections and cancers is outlined in national and international guidelines.

The spectrum of illness seen in HIV-positive patients has changed over the last decade. The use of effective ART in people known to have HIV has led to fewer people requiring inpatient care for immunosuppression-related complications of HIV. To ensure optimal management of these conditions, service provision will need to be delivered via formal networks across geographical areas to ensure that inpatients with advanced HIV have equitable access to best-quality care and advice. Network arrangements will ensure that



HIV services maximise critical mass in order to provide adequate experience to achieve optimal outcomes and support training in inpatient HIV care. In addition, long-term survival has led to an increase in a number of malignancies and other end-organ disease. There will be a need for a network to develop agreed pathways for integrated care for those conditions requiring specialist input, such as lymphoma, multicentric Castleman's disease, co-infection with hepatitis B and C, and end-organ liver and renal disease.

HIV-positive people are living longer and are often admitted to hospital for non-HIV related problems. During hospitalisation they may be seen by a wide range of healthcare staff, some of whom may have limited experience in providing care for people living with HIV. Issues that can negatively impact on patient experience during their stay include fear of breach of confidentiality, fear of stigma and fear of drug errors with HIV medication.

Providers of outpatient HIV care must have documented, agreed pathways to appropriate inpatient services. It is accepted that not all HIV-positive people with proven or suspected complications of HIV require transfer to an HIV specialist unit and they may be cared for safely and effectively locally. They must, however, be supported by immediate and continued engagement with specialist HIV expertise and advice, allowing for early transfer should the complexity of care escalate. Specialist HIV inpatient services must also be in a position to provide support and advice to acute medical services when a patient is clinically unsafe to transfer.

## Quality statements

### Treatment

- People living with HIV requiring admission to hospital should receive the best care and treatment, as defined by nationally recognised guidelines for all patients but also according to the guidelines for the treatment of HIV and its complications.
- People living with HIV should expect that when hospitalised with a suspected or proven AIDS-defining opportunistic infection/cancer and/or with severe immunosuppression, their care is supervised by or discussed with a clinician experienced in the inpatient management of HIV disease. This clinical engagement should be immediate and continuous. In low-prevalence areas their care should be discussed with the designated inpatient unit within the network.

### Care pathways

- People who require admission or transfer to an acute HIV specialist inpatient unit, or who require access to specialist HIV inpatient expertise and advice, should be able to access these services within 24 hours of referral/request.

### Confidentiality, privacy and dignity

- People living with HIV who require inpatient admission should experience high standards of confidentiality, privacy and dignity in line with the law, GMC guidance, Nursing and Midwifery Council (NMC) code of conduct and national standards. People living with HIV have the right to expect that their care is provided in a safe environment and that they are treated with dignity and respect regardless of race, gender or sexuality.



## Communication and discharge planning

- People living with HIV who require admission to hospital should experience effective rehabilitation and discharge planning to ensure timely length of stay, appropriate arrangements for ongoing care and safe discharge.
- Healthcare professionals involved with the ongoing care arrangements of patients discharged from HIV specialist inpatient services should be in receipt of a summary of the treatment and care received and plans for ongoing care within 24 hours of the patient's discharge.

## Infection control

- People with advanced immune deficiency and who are admitted to hospital should be protected appropriately from hospital acquired infection. Service arrangements should be in place to reduce and avoid the risk of hospital acquired infection and to ensure immediate access to appropriate isolation facilities, when needed.

## Care arrangements of HIV inpatient units

- Arrangements for care in specialist HIV inpatient services must ensure there is:
  - ◆ Provision of 24-hour access for acute care
  - ◆ Co-location with high dependency unit (HDU) and intensive therapy unit (ITU) services with appropriate escalation of care to HDU and ITU when indicated
  - ◆ 24-hour availability of pharmacy services and access to specialist HIV pharmacist advice
  - ◆ An HIV specialist consultant physician-led multidisciplinary team
  - ◆ A nursing team with HIV specialist nursing skills and expertise
  - ◆ 24-hour availability of HIV specialist inpatient consultant advice and expertise (locally or via a network)
  - ◆ Access to diagnostic laboratory services as required
  - ◆ Access to other medical and surgical specialty advice and services when required
  - ◆ Access to psychosocial and welfare advice and support, including peer support
  - ◆ Access to dietetic, physiotherapy, occupational therapy and speech and language services, including assessment and provision of inpatient rehabilitation
  - ◆ Provision of 24-hour access to and use of on-site negative pressure units or an agreed pathway in place to nearby facilities
  - ◆ Access to a full range of on-site imaging services
- Arrangements for inpatient care should ensure that access to the above services, advice and provision of results is not delayed.

## Measurable and auditable outcomes

- Proportion of people admitted to a specialist HIV inpatient unit within 24 hours of request for transfer (target: 90%).
- Proportion of specialist HIV inpatient services with documented evidence that they provide 24-hour HIV specialist consultant cover for the management of HIV disease within a designated network including provision of advice to other units within the network.

- Proportion of inpatients presenting with an AIDS-defining condition or serious bacterial infection and CD4 count <350 cells/mm<sup>3</sup> started on, or maintained on, ART within 6 weeks (target: 90% of those surviving).
- Proportion of all patients discharged from an HIV specialist inpatient unit (with an HIV-related problem) seen in HIV outpatient services within 1 month (target: 90%).
- Proportion of all deaths of HIV patients with documented evidence of review of the death, including those admitted to an inpatient unit (target: 95%) (see Standard 8b).

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## 4b. Comorbidities, co-infections and cancers

*People living with HIV should be able to access a comprehensive range of specialist services to manage comorbidities, co-infections and cancers as required. Establishment of clear protocols and agreed pathways for care between primary and secondary care are essential for safe delivery of services*

### Rationale

A combination of an ageing HIV cohort, longer duration of HIV and long-term ART has resulted in a shift from HIV-associated pathology and ill health associated with severe immunosuppression to non-AIDS comorbidities associated with ageing in the general population such as neurological, heart, liver and renal diseases and cancers. HIV services have a key role in screening and monitoring people for complications associated with HIV. Where a service is not in a position to deliver all aspects of HIV related care, it is essential for clinical safety and service sustainability that clear, agreed pathways are established with local or regional specialist and primary care services to allow equitable access and safe delivery of care for people living with HIV. Good communication between services is essential to optimise clinical outcomes and ensure patient safety due to the increase in comorbidities and the complexity of HIV drug-drug interactions.

People living with HIV are at increased risk of certain co-infections, particularly TB, hepatitis B and hepatitis C. Risk factors include immunosuppression associated with advanced HIV in the case of TB, as well as shared routes of transmission between HIV and hepatitis B and C viruses, and higher prevalence of these infections in parts of the world where HIV is endemic, especially sub-Saharan Africa. It is essential, therefore, that people living with HIV are screened for these co-infections both at initial HIV diagnosis and during follow-up, according to national guidelines. Those found to be co-infected should be referred to specialist services for appropriate treatment.

People living with HIV are also at increased risk of certain cancers, including the three AIDS-defining malignancies (Kaposi's sarcoma, B-cell non-Hodgkin's lymphoma and cervical cancer), as well as many other cancers. The care of these patients should be undertaken by a multidisciplinary team, including oncologists, HIV physicians and palliative care physicians where appropriate.

## Quality statements

### Comorbidities

- People attending HIV outpatient clinics should undergo regular screening, as set out in the BHIVA guidelines in order to detect cardiovascular, renal, liver, bone and other comorbidities.
- People living with HIV should have timely access to diagnostic tests required for the detection and investigation of comorbidities.
- People living with HIV should have access to services to manage comorbidities safely and effectively either within the HIV service or in primary care and/or non-HIV specialist teams where appropriate.
- Clear, agreed pathways should be developed to facilitate referral to local or regional services for those with complex and/or less common comorbidities.

### TB

- People with newly diagnosed HIV should undergo full clinical assessment to exclude active TB.
- People living with HIV who are from high and medium TB incidence countries should undergo testing for latent TB.
- Access to rapid TB diagnostic tests and drug sensitivity testing should be available.
- Intensive partner notification services should be available.
- People being treated for HIV and TB should be cared for by a specialist multidisciplinary team that has experience managing TB/HIV co-infection. Best practice infection control should be in place.
- People with rifamycin-resistant/MDR TB should be managed in conjunction with teams with expertise in the management of drug-resistant TB.
- People with TB co-infection should be managed according to BHIVA guidelines for the management of TB/HIV co-infection in adults.

### Hepatitis B and C

- People newly diagnosed and those living with HIV should be screened for co-infection with hepatitis B and C as per BHIVA guidelines.
- People who are co-infected with either hepatitis B or C should be managed according to national guidelines.
- People co-infected with hepatitis C (HCV RNA positive) should be referred to a specialist viral hepatitis clinic for further investigation and treatment with direct-acting antivirals (DAAs).
- People with cirrhosis should be referred to a hepatology clinic for long-term monitoring and management.

### Cancer

- People who are diagnosed with a malignancy should be referred to a centre with expertise in its management.
- Management of people living with HIV who are diagnosed with a malignancy should be in line with the BHIVA Guidelines.



- Clinical networks supporting regional centres of excellence for the treatment of both AIDS-defining and non-AIDS-defining cancers should be developed.
- People with AIDS and non-AIDS-defining cancers should be offered the standard of care given to HIV-negative patients.
- Potential interactions between ART, opportunistic infection prophylaxis and cancer therapy should be considered.
- Those patients with a poor prognosis should be referred to the palliative care team (see Standard 7d).

## Measurable and auditable outcomes

### Comorbidities

- Proportion of people living with HIV with a smoking history documented in the last 2 years (target: 95%) and blood pressure recorded in the last 15 months (target: 95%).
- Proportion of people aged over 40 years with 10-year cardiovascular disease risk calculated within 1 year of first presentation (target: 90%), and within the last 3 years if taking ART (target: 90%).
- Proportion of people with documented assessment of renal function, to include serial assessment of creatinine or eGFR measurements, and proteinuria over the last 24 months (target: 90%).
- Proportion of people aged over 50 years and all post-menopausal women and trans men with documented evidence of bone fracture risk assessment within the last three years (target: 90%).

### TB

- Proportion of people newly diagnosed with HIV from high- and medium-risk countries with documented screening for latent TB (target: 90%).
- Hepatitis B and C
- Proportion of people with documented screening for hepatitis B and C at time of HIV diagnosis or first clinic appointment (target: 95%).
- Proportion of people who are non-immune to hepatitis A or B offered vaccination as per BHIVA guidelines (target: 95%).
- Proportion of people who are co-infected with hepatitis B or C with documented assessment of liver staging (target: 90%) and if ongoing HBV or HCV viraemia, with documented assessment of liver staging in past 15 months (target: 90%).
- Proportion of people with cirrhosis (regardless of cause) with documented hepatocellular carcinoma screening in past 12 months (target: 90%).

### Cancer

- Proportion of services with evidence of network arrangements appropriate to a geographical area to ensure that people requiring specialist oncology services have equitable access to best-quality advice (target: 95%).
- Proportion of people diagnosed with a malignancy linked to specialist oncology services (target: 95%).

References: 11, 49, 82–84



## 4c. Supporting people with higher levels of need

*There is evidence that people living with HIV are more likely than the general population to have multiple long-term conditions, to have poorer mental health, poorer sexual health and to have problems with alcohol and substance use. These issues can lead to an individual having a collection of diagnoses that might be seen as a marker of complexity or increased need.*

The management of HIV in the era of multiple, highly effective, generally safe and well-tolerated treatment choices can seem quite straightforward. There are, however, a number of factors that can act as barriers to successful engagement in care, adherence to treatment and enjoyment of a good quality of life. People living with HIV experience high levels of stigma and discrimination because of their diagnosis but the people affected by HIV are also more likely to be members of communities that are already subject to discrimination and social disadvantage.

People living with HIV are more likely than the general population to have multiple long-term conditions, to have poorer mental health, poorer sexual health and to have problems with alcohol and substance use. These issues can lead to an individual having a collection of diagnoses that might be seen as a marker of complexity or increased need. This approach does not account for individual variation in the ability to manage these problems and the impact on health overall. The person's individual resources, ability to cope, social connection and support, and the wider socio-cultural context are likely to play a major role in determining the effect of a given health problem.

There is no single, validated framework or tool to identify people for whom adhering to HIV treatment and engaging in care requires significant levels of support. While there is considerable awareness of complexity in HIV medicine, at the time of writing there is no validated means for identifying people that might allow 'risk stratification'. Some work has been done in identifying those more at risk of suboptimal engagement in care. NICE has also produced guidance (NG56) that makes recommendations on tailoring care for people with multimorbidity, particularly if any of the following apply:

- They find it difficult to manage their treatments or day-to-day activities;
- They receive care and support from multiple services and need additional services;
- They have both long-term physical and mental health conditions;
- They have frailty or falls;
- They frequently seek unplanned or emergency care; or
- They are prescribed multiple regular medications.

However, there is a paucity of evidence on effective interventions to tackle engagement issues. We recommend that a biopsychosocial approach is used to underpin person-centred care for all people living with HIV. The objective of this approach would be to identify and address factors that are likely to create additional need or vulnerability. It is recognised that some factors, such as poverty, are difficult for service providers to influence. Nevertheless, the formulation with the person concerned of what might be called a 'personalised care plan' or an 'individualised management plan' would allow identification of need, understanding of priorities for that individual and targeting of resources. Ideally such an approach would be shared with all the agencies and services involved with the person, with one agency responsible for the coordination of care. This whole-person

approach to care will require contribution from a number of different agencies and providers across the health and social care spectrum and the third sector, as illustrated in these Standards.

People with several long-term conditions, who face economic hardship and/or who have alcohol or substance use problems are more likely to have mental health difficulties that may be more complex. The standards for psychological care are likely to be of particular importance.

People with multiple needs will often have a number of agencies or services involved in their care, but they may also be the least able to make best use of these services and face challenges in attending the multiple appointments that are often required. A care coordinator role has been successfully used in other conditions such as mental health and is widely advocated for people with complex needs.

Increased need may often come from social disadvantage and responding to issues such as homelessness, immigration issues, intimate partner and gender-based violence, stigma and social exclusion will assist in optimising life outcomes for people living with HIV.

Globally, it is estimated that one in four women experiences violence from an intimate partner (IPV) in her lifetime, making this the commonest form of violence against women. Women living with HIV report higher rates than those in the general population, and IPV appears more likely at the time of HIV disclosure and pregnancy. Screening questionnaires such as the HARK tool (Humiliated, Afraid, Rape, Kick) have been shown to be easy to use and acceptable to women.

There is very little known about the relationship between IPV and HIV in men. However, one study that used a representative sample estimated that 26.9% of gay men had experienced IPV in their lifetimes and 12.1% had experienced IPV in the past year. Studies suggest that transgender people may confront similar, if not higher, levels of IPV as compared to sexual minority men and women and cisgender people. Findings of lifetime IPV among transgender people from purposive studies range from 31.1% to 50.0%.

Services should have robust referral pathways and support for women and men reporting IPV or the risk of this.

People who use drugs represent a group that may be particularly affected by HIV and while the prevalence in this group has remained relatively low in the UK overall, outbreaks can occur. People who use drugs meet many of the NICE criteria outlined above as well as facing numerous challenges in the social and policy climate that could result in poor clinical outcomes. Clinical services and public health organisations should work together to identify and tackle the particular challenges facing this population.

## Quality statements

- People newly diagnosed with HIV should have a comprehensive assessment of their physical and mental health, past medical history, as well as wider determinants of health such as drug and alcohol use, housing, finances, employment, and social support. This should be repeated annually, and used to identify those who may have higher levels of need.
- Where increased need is identified, a 'personalised care plan' should be developed to highlight priorities for that individual and targeting of resources. This should act as a framework for management plans and referrals to other agencies.



- Where social care needs, financial difficulties, housing or other insecurities, are identified, clinics should have as a minimum, signposting to, or information, about sources of advice and support to address these difficulties.
- HIV services should actively prioritise care planning for people with increased needs where there is a clear deleterious interaction with patterns of engagement in care and/or adherence to treatment.
- Enquiry about current or past IPV should be made at baseline in all people newly diagnosed with HIV and this should be periodically reviewed, for example as part of an annual assessment. HIV services should have robust, agreed pathways for referral to support services for people reporting IPV, be able to conduct risk assessments and have staff trained in safeguarding issues of children affected.
- Adherence to ART is likely to be more challenging for people with higher levels of need and thus the choice of treatment is particularly important. Consideration should be given to drug choice that might facilitate adherence for that individual. For example, homeless people may find storage of a large number of boxes of different medications more difficult, so a lower tablet number may be beneficial.
- Interventions should be planned with the person according to needs as well as clearly agreed priorities and aims. Peer support should be offered to all patients, but in this group, there may be particular benefits in providing support in negotiating the health and social care system and reducing isolation.
- A care coordinator should be utilised for people living with HIV with higher levels of need and while not present in all localities, a specialist HIV nurse working in the community may be particularly suitable.
- HIV support services, often provided by the third sector, are of great value in supporting people with higher levels of need. Support provided by clinical and other support services must be as coordinated as possible with strong referral and communication links.
- HIV services should actively identify problems with alcohol and/or drug use in people living with HIV and have robust referral pathways to the relevant support services.

## Measurable and auditable outcomes

- Proportion of people who report intimate partner violence with documented evidence that they have been offered referral to appropriate services (target: 95%).
- Proportion of services with formal arrangements for people with increased needs that are appropriate to a geographical area to ensure they have equitable access to best-quality advice relating to their rights and access to health and social care and their entitlements to public services and assistance.
- Documented evidence of an agreed provider assuming the role of care coordination for a person with increased needs, within the relevant local area (target: 90%).
- Proportion of people with documented evidence of screening for alcohol and/or drug use in past 15 months (target: 90%).
- Proportion of services with an agreed care pathway to drug and alcohol support services (target: 95%).

References: 48, 67, 85-105



# 5. Sexual and reproductive health

## 5a. Sexual health

*People living with HIV should be supported in establishing and maintaining healthy sexual lives for themselves (and their partners).*

*People living with HIV should be supported to protect themselves (and others) from acquiring new sexually transmitted infections, with access to regular screening and prevention interventions for all sexually transmitted infections.*

*People living with HIV should be offered support from staff competent in partner notification with expertise relevant to their individual circumstances. This should enable their personal contacts who are at risk of HIV, including their children, to access timely HIV testing with appropriate consideration of confidentiality and safety.*

*People living with HIV who may be at risk of drug use associated with sex (including chemsex), infectious hepatitis, and sexually transmitted enteric infections (STEI) should be identified and offered support, advice and interventions.*

### Rationale

Good sexual health is part of good overall health. The impact of living with HIV, a potentially stigmatising sexually transmissible infection, which may have been acquired through sexual or non-sexual routes, should not be underestimated, and is associated with sexual dysfunction and psychosexual morbidity. People living with HIV and their partners require access to appropriate, culturally sensitive and effective information and support about sexual behaviour and minimising transmission risks. Practitioners need knowledge and expertise to be able to sensitively discuss sex and sexuality, safer sexual practices, HIV transmission risk in the context of effective therapy and preventative therapy for contacts, HIV disclosure and fear of criminalisation.



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Guidelines produced by BHIVA, BASHH and the FRSH on the sexual and reproductive health of people living with HIV should be followed ([www.bhiva.org/SRH-guidelines-consultation.aspx](http://www.bhiva.org/SRH-guidelines-consultation.aspx)). Practitioners should be up to date on key emerging issues affecting sexual risks, such as chemsex, hepatitis outbreaks, and STEI and be able to counsel and support accordingly. STIs are more common in people living with HIV, and they are at a greater risk of complications from STIs such as hepatitis A, B and C, human papilloma virus (HPV), herpes simplex virus (HSV) and syphilis. MSM who are living with HIV have a higher prevalence of bacterial STIs including syphilis and lymphogranuloma venereum (LGV), viral infections including hepatitis C and of emerging STIs such as STEI.

Prompt identification and treatment of all STIs is important as concomitant infection increases the risks of HIV transmission/acquisition. Those who are living with HIV should be provided with information on STI risks and outbreaks at their routine HIV appointments so they can identify whether additional testing is required. In the case of outbreaks, it may occasionally be necessary to advise and recall prior to the next appointment.

Sexual healthcare should be primarily for the benefit of the individual, and the cornerstone of sexual healthcare is open access to a specialist, confidential service with treatment for STIs provided without charge. The clinical care of the individual person should not be compromised by anxieties about any legal issues relating to sexual transmission of HIV.

Partner notification for HIV (and other STIs) is an important public health strategy, facilitating early diagnosis among known sexual partners, where unprotected sex has occurred in the presence of a detectable HIV viral load. Onward HIV transmission can be minimised by ensuring sexual partners are aware of the presence of HIV within the relationship and by the effective use of ART.

Prevention strategies are key and, as discussed in Standard 1b, include risk-reduction counselling and antiretroviral medication, either as prophylaxis for negative partners or as treatment as prevention (TasP), meaning that a person living with HIV who is on ART and has achieved an undetectable viral load in their blood for at least 6 months cannot transmit HIV to their sexual partners.

It is important to note that an undetectable HIV viral load only prevents HIV transmission. Condoms also help prevent HIV transmission as well as other STIs and pregnancy. The choice of HIV prevention method may be different depending upon a person's sexual practices, circumstances and relationships. For instance, if someone is having sex with multiple partners or in a non-monogamous relationship, they might consider using condoms to prevent acquisition of other STIs.

People living with HIV should be able to access appropriate sexual health support and guidance and may require specific help when telling past and present sexual and/or injecting partners about being HIV positive.

## Quality statements

### Sexual health

- People living with HIV should have easy access to sexual and reproductive health services offering STI screening, treatment and advice according to national guidelines. If this is not provided within the HIV service there should be clear, agreed pathways to sexual health services, ideally with rapid access to facilitate testing and treatment.
- Sexual health assessment should occur at least annually for people living with HIV.

- Syphilis serology should be included in the baseline investigations at the time of initial HIV diagnosis and at regular intervals according to risk thereafter (3-6-monthly or annually, depending on risk).
- People living with HIV should be able to access preventative vaccines for hepatitis A and B, and HPV according to national guidelines and commissioning arrangements, as well as for other STIs, as they become available, and this should be documented.
- People living with HIV should be made aware of the range of interventions that has been shown to reduce risk of onward HIV transmission.
- People who are not on effective ART (for whatever reason) or not yet undetectable should be made aware of the effectiveness of PrEP and PEP for HIV-negative sexual partners according to risk factors.

### Contacts at risk of HIV

- The need for partner notification (PN) support and guidance should be assessed and offered at the time of HIV diagnosis, and if HIV viral load is >200 copies/mL. This should be provided via sexual health services or within the HIV service by those with sufficient expertise, in line with 'HIV partner notification for adults: definitions, outcomes and standards' ([www.bhiva.org/HIV-partner-notification-for-adults.aspx](http://www.bhiva.org/HIV-partner-notification-for-adults.aspx))
- People living with HIV should be offered written and verbal information that is both culturally and age-appropriate about prevention of HIV transmission, including mechanisms for partners to access PrEP and PEP if relevant.
- The risk of onward transmission should be assessed and discussed with people living with HIV, and where necessary risk-reduction interventions based on a theory of behaviour change, such as motivational interviewing and/or a risk-reduction support group should be offered (this includes all those at high risk of STIs).
- People living with HIV should be aware of the importance of avoiding future STIs to which they may be more susceptible, and if acquired may make them more infectious to others in the context of underlying HIV.
- People who have been diagnosed HIV positive should be made aware of the legal position in relation to HIV transmission and how to protect themselves from prosecution; this should occur (and be documented) at the time of their initial diagnosis and subsequently as indicated.

### Measurable and auditable outcomes

- Proportion of people with documented evidence that a full sexual history has been taken and a sexual health screen has been offered within 4 weeks of an initial diagnosis of HIV, and annually thereafter (targets all: 90%).
- Proportion of MSM with documented evidence of syphilis and hepatitis C screening at least annually (target: 90%).
- Partner notification outcomes as listed in 'HIV partner notification for adults: definitions, outcomes and standards' ([www.bhiva.org/HIV-partner-notification-for-adults.aspx](http://www.bhiva.org/HIV-partner-notification-for-adults.aspx)).
- Proportion of people with documented evidence of a discussion about recreational drug use (specifically including chemsex use for MSM and trans people), and the associated STI risks at least annually (target: 90%).

References: 16, 25, 106-108



## 5b. Reproductive health

*People living with HIV should be able to access expert advice and services to enable safe reproductive health, an integral part of HIV care: these include contraception, pregnancy planning and spacing, fertility services, access to abortion services (or referral and support to attend if services are unavailable) and specialist multidisciplinary obstetric services to ensure a healthy infant and woman. Additionally, as women approach the end of their reproductive lives, it is crucial that issues related to the menopause and post-reproductive health are managed to maximise health and minimise the risk of cardiovascular and other adverse events.*

### Rationale

Reproductive decision-making is an important, yet complex part of the lives of people living with HIV. The potential for transmission of HIV through either condomless sexual intercourse or vertical transmission, together with concerns about parental health and longevity, complicate the reproductive decisions for people living with HIV. Regulation of fertility services in relation to HIV has made access more difficult for people who are living with HIV than the general population. Providing reproductive health interventions that are grounded in principles of gender equality and human rights can lead to improved health status and quality of life.

People living with HIV may wish to plan pregnancies, to limit their families, or to avoid pregnancy and, therefore, require advice on and access to the full range of contraceptive methods. Hormonal contraception requires care in prescribing to avoid interactions with some antiretroviral drugs. However, the availability of newer antiretrovirals means that people living with HIV can have a greater choice of contraceptive methods that do not interact with their ART.

People living with HIV may request advice around safe conception and should have access to accurate information and support. Couples may be either seroconcordant (both HIV positive) or serodifferent (one partner HIV positive and one partner HIV negative). Conception by condomless sexual intercourse is the recommended option for serodifferent couples, where the partner living with HIV is on stable suppressive ART (fully suppressed for at least 6 months), and the couple should be counselled that HIV cannot be transmitted in this situation. In the era of routine recommendation of early ART for people living with HIV, and treatment as prevention (TasP), where the partner living with HIV is not on ART, or not on fully suppressive treatment, this should be reviewed and ART offered and/or optimised as appropriate.

Pre-exposure prophylaxis (PrEP) for HIV-negative partners of people with detectable viral loads may be considered to reduce the risk of acquisition of HIV by a partner who is HIV negative. Alternative methods of conception such as self-insemination can enable women living with HIV who are not receiving ARVs to become pregnant without risk of acquisition of HIV by a male partner who is HIV negative. However, people living with HIV should be made aware of the range of interventions that has been shown to reduce the risk of onward HIV transmission.

A major success in the management of HIV has been the prevention of vertical transmission. The high uptake of routine antenatal screening for HIV, coupled with appropriate management for women living with HIV prior to conception, during pregnancy and delivery, and effective postnatal care, results in UK vertical-transmission rates of 0.1-1%.





However, pregnant women living with HIV are particularly vulnerable to psychological and emotional distress and are likely to be at considerable risk of postpartum depression; agreed pathways to assess and respond to mental health issues during and post pregnancy should be in place.

Over 10,000 women of potentially menopausal age (between 45 and 56) attended for HIV-related care in the UK in 2016, a five-fold increase over a 10-year period. HIV and its treatment can predispose women living with HIV to a variety of metabolic complications, many of which are also associated with ageing and the menopause. There is limited evidence to suggest that women living with HIV may experience menopause earlier and with more severe symptoms than women without HIV. As earlier menopause is associated with an increased risk of cardiovascular disease and osteoporosis, it is important that modifiable risk factors for these conditions such as smoking cessation, reducing alcohol intake and increasing exercise are identified and addressed. Menopausal symptoms may also impact on people of non-binary gender and should be considered.

## Highlighting the specific needs of older women living with HIV is an important step in supporting women living with HIV across the life course

Shema Tariq *Principal Investigator, Prime Study*

It is estimated that 85% of perimenopausal women in the general population experience menopause symptoms including hot flushes, sleep disturbance or mood change. Menopause hormone therapy, MHT, (previously referred to as hormone replacement therapy) has been shown to alleviate these symptoms in HIV-negative women as well as women living with HIV. Use of MHT is underutilised in women living with HIV, and in the absence of evidence on best management strategies for menopausal women living with HIV (including the efficacy and safety of MHT), management should be in accordance with current NICE menopause guidelines. MHT (both systemic and topical) is not contraindicated in women living with HIV for the management of menopausal symptoms. There may be drug interactions with some antiretroviral agents, requiring dose titration of MHT according to symptoms. In addition, topical vaginal oestrogens have very little systemic absorption with no drug interactions, and can greatly alleviate urogenital symptoms of the menopause.

### Quality statements

- The reproductive health needs of people living with HIV should be addressed by the availability of expert counselling and support within HIV services.
- People living with HIV should have access to accurate information about the full range of contraceptives and pregnancy choices, including specialist advice on potential drug interactions. This should be available within the specialist HIV unit, and pathways should be developed with dedicated local contraceptive services (with knowledge of the issues pertaining to HIV) for provision of contraception.
- In accordance with the BHIVA/BASHH/FSH Sexual and Reproductive Health guidelines, management of menopause should be in primary care wherever possible, with close liaison with HIV services. Pathways with specialist menopause services should be established for complex cases.
- People living with HIV should have access to accurate information about the menopause (including symptoms and management options) within the clinic.
- People living with HIV should have access to accurate information and support for



safe conception, including pre-conception advice for themselves and their partners within their specialist HIV unit.

- People living with HIV should have access to accurate information and support for pregnancy choices, including abortion, within their specialist HIV unit.
- People living with HIV who require investigation and treatment for infertility should be able to access local or regional fertility/conception services through agreed pathways.
- Centres with obstetric units need explicit, agreed pathways both to ensure access to immediate HIV testing for labour presentation, the appropriate handling of HIV serology results identified through the antenatal screening programme and to enable those with HIV-positive results rapid consultation with the HIV and pregnancy multidisciplinary team (outlined below).
- Appropriate timelines for review by the HIV and pregnancy multidisciplinary team are:
  - ◆ Within 10 working days from the date of the initial HIV-positive result: for an asymptomatic pregnancy, newly diagnosed HIV positive, booking before the end of the first trimester
  - ◆ Within 5 working days of the initial HIV-positive result: for an asymptomatic pregnancy, newly diagnosed HIV positive, booking after the end of the first trimester or if any interventional diagnostic procedures are planned
  - ◆ On the same day: for a pregnant woman, newly diagnosed HIV positive, who has HIV-related symptoms, or is within days of the expected delivery date
  - ◆ Immediately: for a pregnant woman, newly diagnosed HIV positive, or with a new reactive point-of-care test in labour
- The management of pregnancy, childbirth and the immediate postnatal period should be in line with current national guidelines and undertaken by a specialist multidisciplinary team (to include obstetrician, HIV specialist physician, specialist midwife, specialist HIV pharmacist and paediatrician and ideally peer support where available) with expertise in HIV and pregnancy. Designated individuals within an organisation or network should be identified.
- People living with HIV should have access to accurate information on the full choice of postpartum contraceptives, recognising that barrier methods will also protect against STIs, and these should be accessible immediately postpartum.
- Provision of ART in pregnancy is within the scope of an outpatient HIV unit, but birth plans and plans for paediatric care should be managed in collaboration with obstetric services and local/regional paediatric HIV teams.
- Services should ensure that information on ART and its risks and benefits supports the key decision issues of whether to start, change or cease treatment, using ART during pregnancy, and the impact of treatment to protect sexual partners (see Standards 2b, 3c and 5a).
- People living with HIV should have access to the full range of interventions that has been shown to reduce the risk of onward HIV transmission to their child, including provision of free infant formula milk for those who are unable to afford it.
- Appropriate counselling, monitoring and support, as per current national guidelines, should be available for people making an informed decision to breastfeed their infants.
- People living with HIV who have children with HIV should be offered the option of

combined outpatient family care, allowing treatment of adult(s) and children in the same visit.

- People living with HIV should have access and/or referral to peer support as outlined in 'National Standards for Peer Support in HIV', particularly during pregnancy.

## Measurable and auditable outcomes

- Proportion of people with documented evidence of a discussion of current reproductive choice and current contraception during a 15-month period (target: 90%).
- Proportion of women and trans men aged 45–56 years old with documented discussion about menopause and enquiry about symptoms (target: 90%).
- Proportion of services with agreed care pathways for contraceptive, conception, fertility and menopause assessment and management.
- Proportion of pregnant people with documented evidence that care plans, to be employed by the multidisciplinary team, are in place. The care plan should cover pre-, intra- and postpartum care and paediatric follow-up and should be available at the point of care (target: 95%).
- Proportion of services with documented evidence of reporting all known to have HIV to NSHPC in accordance with existing arrangements.

References: 2, 6, 109–113





## 6. Psychological care

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

For people living with HIV to be able to access psychological care it is necessary to have clear standards, referral pathways, screening, and interventions. While there has been a growing recognition of the importance and parity of mental health alongside physical health, resources and provision have been restricted. Language and terminology in this area can be confusing and controversial, with different words used by different groups. These Standards use the following terms:

- Emotional well-being: the emotional, practical, and lived experiences of people living with HIV (e.g. stigma, telling others about one's status, relationships, sex, employment, travel);
- Mental health: diagnostic labels such as anxiety, depression, post-traumatic stress disorder, insomnia, suicidal thoughts and self-harm, and addictions;
- Cognitive functioning: the neurological health of the brain and how this is expressed cognitively (including memory, language, processing speed) and how HIV, its treatment, and other health and lifestyle factors can sometimes affect this.

These Standards draw upon the 'Standards for Psychological Support for Adults Living with HIV' and the two should be read in conjunction. Key to this is the stepped-care model in which the psychological care needs of people living with HIV should be considered and managed by all health and social care providers they encounter, with self-help and peer support throughout (Figure 1, Table 1).

**Reference:** 116

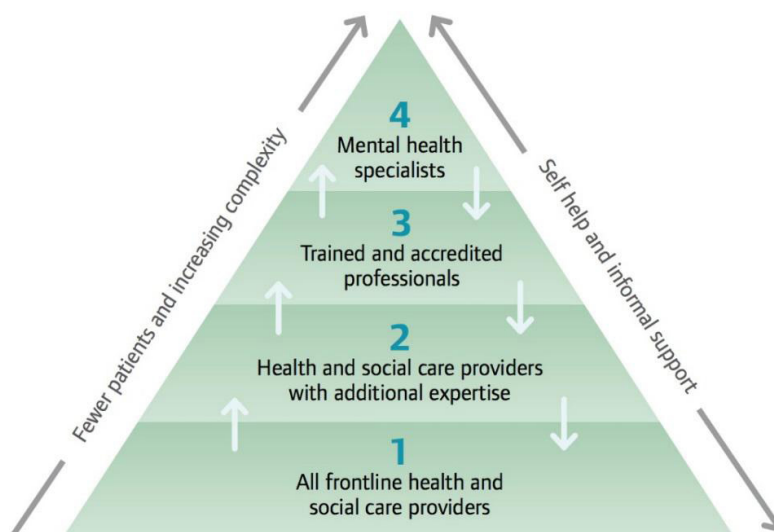


Figure 1. Stepped-care model of psychological support for adults living with HIV (2011)



## 6a. Emotional well-being

### Rationale

While medical treatments for HIV have advanced considerably over the past 30 years, people living with HIV report that the ignorance and fear around HIV that can breed stigma persists, both from the general public and within the healthcare system. HIV stigma can significantly affect quality of life and impact upon health behaviours of people living with HIV (e.g. seeking and taking treatment, discussing status with others) (see Standard 2a). Some people living with HIV internalise stigma into feelings of shame, guilt and disgust (self-stigma), which can contribute to depression, anxiety and hopelessness, or find themselves in relationships involving intimate partner violence that reinforces these negative messages. It is acknowledged that challenging HIV stigma requires change at individual, policy and organisational levels. For example, message-specific campaigns addressing discrimination or the role of undetectable viral load upon infectiousness could help address stigma, and these messages should be promoted by HIV services to both people living with HIV and the wider public.

In addition to stigma, people living with HIV will have to manage a chronic illness and the daily and cumulative impact this can have on their psychological well-being (e.g. access and adherence to medication, possible side effects, health uncertainty, medical appointments, changes to benefits and social care). As such it has been suggested that the UNAIDS 90-90-90 target (90% people living with HIV diagnosed, 90% of these on treatment, and 90% of these virally suppressed) be expanded by a 'fourth 90' of good health-related quality-of-life. Finally, as HIV care continues to evolve with continued improvements to treatment, there has been a shift to self-management and/or primary care. While this can have many benefits, the loss of previous patient-clinician relationships for people living with HIV can be profound, and be an added psychosocial stressor.

Despite this, the majority of people living with HIV manage their physical and mental health and well-being effectively, showing strength, growth and resilience in often challenging circumstances; for example, drawing upon social relationships (e.g. partner, friends, family), faith, professionals and external agencies as required. In addition, a vital resource in the support of people living with HIV with stigma and illness burden is other people living with



HIV. Peer activism, advocacy and support have always been a bedrock of HIV care, adapting to changing financial climates, technologies and medical advances. It includes online and App-based information and forums, as well as face-to-face individual and group meetings. These can range from educational (e.g. newly diagnosed courses, patient networks), skills-based (e.g. mindfulness, benefits support) and informal social and recreational gatherings. Some are formally supported and hosted within NHS HIV services, while others are based within local or national charities and organisations.

## Quality statements

- The potential burden of living with and managing a chronic illness should be routinely monitored for people living with HIV.
- All people living with HIV should have access to peer and psychosocial support, and advice according to national standards. There should be agreed pathways in place for those with more serious psychological or cognitive difficulties, which ensure early detection of the problems and prompt referral to appropriate services.
- Peer support should be discussed and made available to all people living with HIV, and form part of their clinical care pathway options.

## Measurable and auditable outcomes

- Proportion of people with documented evidence at annual review of key well-being indicators in chronic illness management beyond physical and psychological health (e.g. satisfaction with care provided and self-management) (target: 80%).
- Proportion of all new patients with documented evidence of discussion of peer and emotional support and sign-posting to appropriate services as required (target: 90%).

**References:** 40, 117, 123, 125, 126

Level 1	Key information, support and signposting that can be provided by all staff working with people living with HIV  e.g. healthcare assistants, health advisors, nurses, pharmacists, doctors
Level 2	Enhanced support that screens for difficulties or provides brief interventions (e.g. psycho-education, motivational interviewing)  Staff with extra training and supervision: e.g. nurses, health advisors, peer mentors
Level 3	HIV-specialist psychological therapies, counselling, cognitive screening and pharmacological interventions that are HIV-specific for common mental health difficulties (e.g. anxiety, addictions, moderate depression, psychosexual or relationship issues, post-traumatic stress) and HIV-related issues  Qualified and accredited clinicians: e.g. clinical and counselling psychologists, advanced nurse practitioners, general practitioners, dietitians, physiotherapists, psychiatrists, occupational therapists

Table 1. Examples of interventions and healthcare groups within stepped-care model

## 6b. Mental health

### Rationale

Studies have found higher rates of depression, anxiety, post-traumatic stress disorder, insomnia, addictions, self-harm and suicidal thoughts, and enduring mental health issues among people living with HIV compared to the general population.

The reasons for this are complex and include: a higher risk of HIV acquisition in people with pre-existing mental health difficulties; traumatic life events and substance use; the impact of living with a stigmatised, chronic medical condition; and potential side-effects of antiretroviral treatment (either causing unpleasant physical health symptoms or neuropsychiatric interactions directly causing or exacerbating mental health symptoms).

Some challenges will be relevant to all people living with HIV, whilst others affect specific key populations (e.g. black MSM, trans women, drug users, those in prison, sex workers and people living with disabilities).

**People living with HIV need to be seen as a whole not just a viral load, and becoming undetectable is not seen as the end game, our journey of living with a stigmatised condition can be an ongoing psychological burden if not supported or addressed**

*Mel Rattue, Positively Mindful*

Not only does mental health negatively affect quality of life, it can create a vicious cycle as it can complicate clinical care (e.g. disengagement from healthcare systems, non-adherence to ART), thus compromising physical health and heightening the risk of onward HIV transmission. However, recent audits have found variability in the extent to which mental health screening is conducted, and concerns regarding access to relevant mental healthcare services when detected.

Therefore, the assessment, management and promotion of mental health for people living with HIV is of critical importance, and is recommended following diagnosis and other events known to trigger or exacerbate psychological distress or cognitive difficulties (e.g. significant changes in physical health, starting or changing ART, difficulties with adherence, re-engaging with clinical care after being lost to follow-up, significant life events such as a difficult relationship break-up, experiencing stigma or violence, losing benefits, or sudden death of a loved one) and on an annual basis thereafter.

Assessment involves regular screening for common mental health difficulties (by clinical questioning and/or specific and validated measures) with appropriate and timely escalation to relevant services if concerns are noted, utilising the stepped-care approach (Figure 1). Clear referral pathways with effective and defined communication channels should be established between HIV services and those providing mental healthcare, to minimise fragmentation, with the person living with HIV included in communication whenever possible. Any possible barriers to referral should also be anticipated and addressed (e.g. language and translation needs, geographical residency of person and service, the service's views on working with dual diagnosis, for example, drug use).



## Screening measures

Specific screening tools should not be seen as a replacement for an individual discussion about mental health with a specialist HIV consultant or GP, with whom the person living with HIV may have a long-standing relationship. Equally mental health can fluctuate or be episodic, and many screening questions relate to a specific and recent period of time which may not coincide with a person's difficulties. Conversely, however, being asked 'How are you?' will not necessarily prompt a discussion of depression, anxiety, insomnia, cognitive issues, PTSD and so on. Therefore, mental health screening can help clinicians and people living with HIV to identify a need and refer to appropriate support.

Furthermore, some people living with HIV may not consider accessing mental health services even if they identify as being depressed or anxious. This may be because they perceive this level of emotional (ill) health as expected, and may not necessarily have an awareness that it could be improved with interventions. There can also be stigma associated with accessing mental health services, especially in some cultural groups such as black and minority ethnic communities and men, and so for these reasons people living with HIV may under-report their difficulties in consultations.

There is a recognised need for national standardised screening measures for mental health; however, this is not currently possible due to the lack of evidence. Clinical opinion will need to inform the selection of tool(s) used, which may vary depending on the person living with HIV, cultural differences, and norms available. A non-exhaustive list of some commonly used measures is provided in Appendix 6.

## Intervention

The management of the issue(s) present will depend on the severity and complexity of the mental health difficulty, evidence-base, and the person's preference, and should be provided by appropriately qualified providers following relevant clinical guidance.

It is beyond the remit of this Standard to explore all potential mental health difficulties and the HIV-specific evidence base (or lack thereof) for each. Rather, good care should be both culturally competent with respect to the unique facets of living with HIV, account for patient choice, and be evidence-based. This may include both long-established psychological and psychiatric interventions as well as emerging therapies (e.g. mindfulness-based cognitive therapy and prevention of depressive relapse or recurrence, and mindfulness-based stress reduction and psychological and HIV health outcomes). This paradigm is known within psychological therapies as the 'what works for whom' approach.

If the mental healthcare professional is not based within the HIV service, they should access research literature, training, consultation or supervision with HIV-specific knowledge and cultural competencies (e.g. neuropsychiatric side-effects of ART as a differential diagnosis, drug-drug interactions between ART and psychotropic medications, stigmatised minority groups).

When working with people living with HIV careful attention should be paid to their lifespan stage (e.g. adolescence, young to middle adulthood, older age, end of life) and personal demographics (e.g. gender, race and ethnicity, migration status, religion and sexual orientation) as these, and the interaction between them, may serve as either resilience or stress factors for their psychological well-being and mental health, and affect both how they understand and access services. As such, any biopsychosocial assessment should formulate lifespan and demographic variables as part of person-centred care.



## Quality statements

- The mental health needs of people living with HIV should be screened on an annual basis and following potential trigger events, including a review for any symptoms of: depression, anxiety, post-traumatic stress, sleep difficulties, addictions, self-harm and suicidal thoughts, with timely referral to appropriate services as required.
- Referral pathways between HIV and mental health services (including addiction services) should be clearly defined, with clear and effective communication to coordinate care, with the person living with HIV included in this whenever possible.
- The mental healthcare professional working with someone living with HIV should provide evidence-based care for the problem(s) identified in a way that maximises the person's choice.
- The mental healthcare professional working with someone living with HIV should have up-to-date HIV-specific knowledge and cultural competencies (including lifespan and demographic variables, and antiretroviral psychotropic side-effects and interactions), access research literature, training, supervision or consultation as necessary.

## Measurable and auditable outcomes

- Proportion of people with documented evidence of annual screening for mental health difficulties (target: 90%).
- Proportion of services with an agreed care pathway for mental health assessment and management (target: 95%).

**References:** 32, 109, 114, 115, 118, 119, 122, 124, 127-131, 133-135

# 6c. Cognitive function

## Rationale

Cognitive disorders are difficulties with brain processing that cause problems with cognitive function and domains such as memory, language, problem solving, attention or processing speed. They remain frequently reported in people living with HIV, despite virological suppressive ART. The prevalence of cognitive impairment in people living with HIV is challenging to ascertain, given that several different diagnostic criteria have been utilised, with a reported range of between 5% and 50%. In addition, delirium is a common acute cognitive function disorder in hospitalised or critically ill people living with HIV and can also be a presenting symptom of undiagnosed acute HIV.

While the true prevalence may never accurately be known (and is liable to change as HIV management and treatment develops) a significant proportion of people living with HIV do experience cognitive disorders or neuropsychiatric side-effects to ART, and thus should be assessed and managed. Furthermore, cognitive symptoms may be misdiagnosed as mental health difficulties, or conversely mental health issues may be incorrectly attributed to cognitive health, and additionally substance use can cause short- and long-term cognitive effects. Therefore, questioning for mental health and substance use should always occur alongside questioning for cognitive disorders.



People living with HIV should be questioned for symptoms of concentration or memory difficulties, or alternatively many short/brief screening cognitive tests and batteries exist (Appendix 6). None of these replace a full neuropsychological assessment but may be useful in determining who should be referred for full assessment. Some screening tests are generalist and some in theory 'HIV specific'; however, all have their limitations.

Should screening tests or clinical presentation indicate possible difficulties then a full neuropsychological assessment may be warranted, which will be conducted by a clinical psychologist. There are a variety of different neuropsychological assessment tests available, assessing different cognitive domains. As with screening tests there is no gold-standard test or tests, rather the selection of tests used will depend on different factors such as the approach used (e.g. hypothesis versus battery driven), as well as available norms, experience of the assessor, if re-testing is planned, and what tests are available locally.

Cognitive rehabilitation strategies or services should be offered as soon as HIV-associated cognitive impairment is detected (alongside mitigation of other cognitive risk factors and neurological review) and be based on a compensatory rather than restorative approach. If antiretroviral neurotoxicity is suspected as the cause of cognitive impairment, then the ARVs should be reviewed.

## Quality statements

- People living with HIV should be questioned annually for symptoms of cognitive or memory decline.
- If cognitive functioning symptoms are reported, and other likely causes such as depression excluded, then further screening and potentially full neuropsychological assessment by a qualified practitioner should be offered.
- If cognitive difficulties are identified, then a detailed HIV-neurology review should be considered, and rehabilitation strategies/services should be offered.

## Measurable and auditable outcomes

- Proportion of people with documented evidence of annual screening for difficulty with cognitive functioning (target: 90%).
- Proportion of services with agreed care pathways for neuropsychological and neurological assessment and management by qualified practitioners (target: 95%).

References: 120, 121, 132



# 7. HIV across the life course

## 7a. Young adults and adolescents living with HIV

Adolescents, as defined by WHO, include all young people aged 10–19 years, and all young people aged 20–24 years. The Standards refer to young adults and adolescents living with HIV, regardless of mode of transmission route and cared for within adult services or transitioning. For adolescents within paediatric care, please refer to the Children’s HIV Association (CHIVA) Standards, which should also be used for transition ([www.chiva.org.uk/files/8015/0642/1695/CHIVA\\_STANDARDS\\_2017.pdf](http://www.chiva.org.uk/files/8015/0642/1695/CHIVA_STANDARDS_2017.pdf)).

### *Transition of care from paediatric to adult services*

*Young people should have access to a formal transition process as they move from children’s to adult HIV services and this should occur over a period of time and take into consideration the young person’s needs, development, maturity, any specific learning or physical disabilities and psychosocial needs.*

### Rationale

**Transition** is defined as ‘a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated healthcare systems. [136]’ The UK National Service Framework (NSF) sets clear recommendations for transitional care supported by a wealth of Department of Health (DoH) guidance and resources. In contrast, transfer is the physical event of the young person moving from paediatric to adult services and, if unsupported, has been associated with increased morbidity and mortality.

Different models of transition exist with no superior model identified and the model chosen is determined by the patient group, available resources and geographical setting. Evidence suggests a documented transition programme with a person-centred individualised

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approach. Meeting the adult team prior to transfer enhances attendance, reduces morbidity and improves patient and carer satisfaction. Individualised transition plans are required that are appropriate for age, developmental stage and social circumstances as the young person moves from paediatric to adult care.

## Access to care

*Young adults and adolescents living with HIV should have access to HIV care and additional support that is accessible, young-person friendly and meets 'You're Welcome' accreditation standards.*

### Rationale

Adolescence is a period of emotional and personal development and high rates of loss to follow-up have been reported in young people transitioning from paediatric to adult care. Young people may display risk-taking behaviour including poor clinic attendance and suboptimal adherence to medication. Young people living with HIV may attend specific young person's HIV clinics or be seen in adult clinics and are likely to need additional support, whether accessing HIV care for the first time or following transition from paediatric services.

Young adults and adolescents living with HIV have complex medical and psychosocial needs, and are likely to have experienced past physical illness and have significant antiretroviral exposure and drug resistance. Those with perinatally acquired HIV may have experienced bereavement or witnessed ill health in other family members. High rates of mental health difficulties and suicide risk have been reported in young adults and adolescents living with HIV.

Peer support enables young adults and adolescents living with HIV to meet other young people in similar circumstances, boosting confidence and self-esteem, and allows a safe space to discuss HIV. It may provide support with adherence or help escape isolation, particularly for young adults and adolescents living with HIV outside large cities where it can be accessed remotely (e.g. via Skype or facetime).

## Sexual health

*Young adults and adolescents living with HIV should have easy access to sexual healthcare and contraception services including the provision of long-acting reversible contraception (LARC).*

### Rationale

Young adults and adolescents living with HIV are at high risk of unplanned pregnancies and may find it hard to negotiate condom use. They may need extra support with issues such as disclosure of their HIV status to sexual partners and forming healthy relationships. Support should come from experienced staff such as health advisers or specialist nurses. Contraceptive advice that takes into consideration antiretroviral drug interactions should be provided by someone with appropriate expertise, with fast-track access to LARC where required (see Standard 5b).

All adolescents are vulnerable to sexual exploitation, coercion and sexual assault. Young adults and adolescents living with HIV may be even more vulnerable as they may have co-existing vulnerabilities such as complex social circumstances, physical ill health, mental health difficulties or substance misuse. Young adults and adolescents living with HIV should be regularly assessed for signs of sexual exploitation and other vulnerabilities. A proforma such as 'Spotting the Signs' should be used with all under 18s and any older adolescents felt to be at risk of child sexual exploitation (CSE). For those accessing a sexual health service, it is recommended that a risk assessment should be undertaken at each attendance with a new problem, more frequently if vulnerabilities are identified, or annually as a minimum. For young adults and adolescents, those not initially considered to be at risk may become so, so practitioners should be aware of the risk factors, and how to assess them. This assessment should be undertaken at least annually within the HIV service, bearing in mind that sexual activity/exploitation/risk may not be disclosed. If the young person is sexually active then it should be done at each visit up to the age of 18, and should continue in those who have been at risk of CSE or have been victims of it or with particular vulnerabilities including a learning disability above this age.

## Management of ART

*ART should be individualised to take into account the specific needs of young adults and adolescents with respect to their physical and neurocognitive development and psychosocial needs*

### Rationale

For all young adults and adolescents living with HIV, ART choices should be in accordance with BHIVA, CHIVA ([www.chiva.org.uk/guidelines/](http://www.chiva.org.uk/guidelines/)) and Paediatric European Network for Treatment of AIDS (PENTA, [penta-id.org/hiv/treatment-guidelines/](http://penta-id.org/hiv/treatment-guidelines/)) treatment guidelines. However, specific considerations should be given to the ongoing physical and neurocognitive maturation that continues well into the third decade of life.

Peak bone mineral density (BMD) is achieved at around 25 years of age and reduced peak BMD is associated with increased risk of fracture in later adult life. Young adults and adolescents living with HIV are at increased risk of reduced BMD compared to the general population of young people. Interventions to improve bone health are most effective during skeletal growth prior to peak bone mass accrual.

Neurocognitive development continues into the middle of the third decade. Young adults and adolescents living with HIV have increased rates of neurocognitive disorders compared to the general population. Mental health difficulties frequently first present in adolescence/young adulthood. Young adults and adolescents living with HIV have increased rates of mental health diagnoses compared to their peers. Avoidance of ARV agents associated with an increased risk of mental health toxicities is recommended.

Adherence to ART is poorer in adolescence when compared to children or adults. Once-daily regimens with a higher genetic barrier to resistance and fixed-dose combinations reducing pill burden should be considered, with adherence support from the multidisciplinary team including access to peer support.

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## Quality statements

### Transition of care from paediatric to adult services

- All young adults and adolescents living with HIV should have an individualised transition plan in line with national guidance.
- Services caring for adolescents living with HIV require a named lead for transition in both paediatric and adult care.
- Adolescents living with HIV should meet their adult healthcare providers prior to transfer.
- Prior to transfer each adolescent requires a comprehensive medical and psychosocial summary.

### Access to care

- Clinics providing care to young adults and adolescents living with HIV should meet 'You're Welcome' accreditation standards.
- Clinics should be provided at convenient times, including clinics after school, college or work, and in easily accessible locations if possible.
- Feedback about the service should be actively sought and should be acted on.
- Young adults and adolescents living with HIV should have access to mental healthcare including psychological support.
- Young adults and adolescents living with HIV should have access to peer support, whether directly provided within clinic or through referral to external agencies.

### Sexual health

- Young adults and adolescents living with HIV should have access to sexual health and contraception services within clinic or via agreed referral pathways to these services.
- Young adults and adolescents living with HIV should be assessed at least annually for signs of sexual exploitation and other vulnerabilities in line with above recommendations.
- Young adults and adolescents should be taught how to protect themselves and others from acquiring STIs. This should include discussions regarding ART as prevention, including discussion that a person living with HIV who is on ART and has achieved an undetectable viral load in their blood for at least 6 months cannot transmit HIV to their sexual partners (see Standard 1b).
- Young adults and adolescents should be informed about the indications for post-exposure prophylaxis (PEP) and pre-exposure prophylaxis (PrEP) in sexual partners, for example, where adherence is suboptimal or viral load is detectable.
- Young adults and adolescents living with HIV should be made aware of the legal position in relation to HIV transmission, and how to protect themselves from prosecution, this should occur (and be documented) at the time of their initial diagnosis and subsequently as indicated.



## Management of ART

- Young adults and adolescents living with HIV require optimisation of bone health with vitamin D measurement and supplementation and substitution of tenofovir with abacavir, if HLA-B\*5701 and resistance assays allow, or with tenofovir alafenamide (TAF) as per NHS England guidance ([www.england.nhs.uk/wp-content/uploads/2017/03/f03-taf-policy.pdf](http://www.england.nhs.uk/wp-content/uploads/2017/03/f03-taf-policy.pdf)). Young adults and adolescents living with HIV require optimisation of mental health and avoidance of ARV agents associated with CNS toxicities is recommended.
- Regimens with high a genetic barrier to resistance should be considered for young adults and adolescents living with HIV initiating or restarting therapy.
- Young adults and adolescents living with HIV should have documented adherence assessment at each clinic and access to adherence support

## Measurable and auditable outcomes

### Transition of care from paediatric to adult services

- Proportion of young adults and adolescents living with HIV with documented evidence of having met the adult team prior to transfer from paediatric to adult care (target: 90%).
- Proportion of young adults and adolescents living with HIV who are transitioning with documented evidence of a comprehensive medical and psychosocial summary of paediatric care being provided to the adult service (target: 90%).
- Proportion of services with named leads for transition in both paediatric and adult care.
- Proportion of young adults and adolescents living with HIV (aged 16–25 years) who attend at least two clinic appointments within a 14-month period (target: 80%).

### Access to care (see Standard 3a)

- Proportion of services compliant with 'You're Welcome' accreditation standards.

### Sexual health (see Standards 1b and 5a)

- As children develop emotionally and physically at different ages, the denominator applied for each auditable outcome may vary and is likely to be less than the relevant clinic cohort, thus all outcomes below are prefaced with 'Where appropriate':
- Proportion of young adults and adolescents living with HIV with documented evidence of assessment of sexual history and contraception status at each routine clinic visit (target: 90%).
- Proportion of young adults and adolescents living with HIV with documented evidence of discussion on legal implications for HIV transmission (see Standard 5a) (target: 90%).
- Proportion of adolescents (under 18 years) living with HIV with documented evidence of use of 'Spotting the Signs' or other CSE vulnerability check list at least annually (target: 90%).

**References:** 24, 136–141

## 7b. Early to middle adulthood

### Rationale

These Standards for early to middle adult life refer to those aged between 25 and 65 years, and will include people diagnosed in childhood, adolescence or early adult life, and who have acquired HIV both perinatally and behaviourally. Young people are defined by the WHO as 'adolescents' when aged 10–19 years, and 'young adults' when aged 20–24 years. Adults are defined as those aged from 25 years, a chronological age at which the complex neuronal pruning of adolescence nears completion, of peak bone mass accrual and typically a move from education to employment. While definitions of adulthood vary it is generally accepted that early adulthood includes those aged 25–44 and middle adulthood, those aged 45–65 years and spans the period of reproductive health and maximal employment.

People who received care within paediatric and adolescent services may have to negotiate a second transition of care from specialist youth to general adult HIV services. Transfer of care is associated with a higher risk of loss to follow-up and young adults have poorer outcomes at all stages of the HIV care cascade when compared to older adults, with Public Health England (PHE) data suggesting that those who acquired HIV perinatally have the lowest rates of viral suppression. Data in young adult life raises concerns of increased risk of malignancy, suboptimal bone mass accrual, and mental health concerns. In addition, a proportion of those who acquired HIV perinatally will live with the long-term consequences of infantile HIV encephalopathy.

Most people of these ages, however, are diagnosed as adults. Owing to the trend of earlier diagnosis and earlier ART initiation, increasing proportions of people living with HIV have experienced no or minimal HIV-related health problems. Most will be in education, training or employment and will often need services that are streamlined and allow minimum disruption to their lives. However, significant numbers of people will have heightened vulnerabilities due to one or more of a number of different factors including late diagnosis, long duration of HIV, toxicity of early ART, anxiety and depression, drug and alcohol dependency, poor housing, stigma, poverty and immigration status. It is important that services are configured to meet the needs of people in these disparate categories and be sensitive to the fact that people move between non-complex and complex categories. In such cases, they will have enhanced care needs (see Standard 4).

Current evidence suggests that people living with HIV experience higher levels of depression, anxiety and other mental health issues so it is important that mental health is routinely assessed and services are in place to support all people living with HIV (see Standard 6).

Most people in these age groups are sexually active and supporting people to have healthy and fulfilling sex lives is a major part of service provision. Emphasising and reinforcing the role of treatment as prevention (TasP) in negating transmission risk is critical (see Rationale, Standard 1b). Additionally, supporting people to plan and achieve their wishes to have children is paramount (see Standard 5). Key elements of sexual and reproductive health services to be provided, or facilitate access to, include providing information, partner management (including testing, PrEP), contraception, sexually transmitted infection screening and treatment, pre-conception planning, assisted conception, antenatal services, and psychosexual services.



Employment and housing are critical factors that strongly impact aspects of health including HIV. Supporting the achievement and maintenance of these is an important role of HIV services through links into strong community support services.

The regular contact with health services that forms the mainstay of routine HIV follow-up offers opportunities to positively impact longer-term health. Interventions range from supporting healthy lifestyles, through to providing vaccinations to regular risk factor assessment and management. Screening for possible alcohol and substance misuse should be undertaken at least annually and appropriate interventions initiated.

## Quality statements

- Adults with perinatally acquired HIV are at risk of poor health outcomes that differ from those who acquired HIV as adults. Services should be able to assess and manage the full range of conditions that can present.
- For those aged 25–65 years, education, training and employment are key elements of health and well-being. It is important that the impact of HIV on these is assessed especially at critical points such as at HIV diagnosis, ART commencement, inpatient care, co-infection diagnosis or treatment.
- Where appropriate, continuity with education, training and employment should be supported, especially through periods where people living with HIV have increased vulnerability.
- Where continuity is not appropriate, care providers should provide support to help people maintain adequate income, housing and social support. This support will include providing timely care summaries detailing health status as well as linking people to community and other support services.
- Care providers should support people living with HIV and act as their advocates if there is evidence that they are being discriminated against in education, training or employment on the basis of HIV.
- The majority of people living with HIV in these age groups are in employment and have good health. Services should be structured in such a way as to minimise the time that people need to take off work to undertake their routine care. Important features of such care for stable patients includes 6-monthly visits (including 6-monthly ART prescriptions), and where possible remote access (such as through internet, telephone) for booking, results and results management, and emergency prescription requests.
- Services need to be responsive when people on a stable, non-complex pathway develop one or a number of complexities. Competent assessment and management needs to be available either in-service or by established referral pathways.
- Compact (including single tablet) regimens are reported to support adherence in some people in some settings including in those undertaking frequent work-related travel, and those sharing accommodation where HIV status has not been disclosed. Commissioning guidance that allows some flexibility to individualise regimens where there is indication of benefit should be available.
- Supporting healthy lifestyles through the young to middle adult years is especially important and potentially has an important impact on health in later years. Key elements relate to smoking, drug and alcohol use, sex, diet and exercise. These parameters should be regularly assessed, and people supported to modify behaviours that improve their health. Support will range from providing information through to short interventions (e.g. motivational interviewing), and referral to specialist services (e.g. smoking cessation, drug and alcohol services and dietetics).



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## Measurable and auditable outcomes

- Issues and the associated quality statements that are specifically relevant to early and middle adulthood age are highlighted above. The measurable and auditable outcomes can be found in the relevant sections.

References: 142-144

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## 7c. Older age

Older age is a significant consideration in the provision of HIV care for two distinct reasons. Firstly, there is an increasing number of people ageing with HIV as a direct result of treatment efficacy. Secondly, there is an increasing number of people being diagnosed with HIV in older age, partly as a result of changes in the epidemiology of HIV in the UK. Issues of health and well-being related to ageing intersect with those of HIV and may give rise to increased complexity in clinical and service delivery. Issues that are specifically relevant to older age are highlighted below and the associated quality statements and measurable and auditable outcomes can be found in the relevant section.

Our knowledge about the relationship between ageing and long-term HIV is emerging and is likely to change considerably over the lifetime of these Standards.

### Testing, diagnosis and prevention

There has been an increase in the number and proportion of people over 50 years being diagnosed with HIV and these are more likely to be late diagnoses. The exposure profile of older people being diagnosed with HIV also differs from that of younger populations, including, for example, higher proportions of heterosexually identified people. Promotion of testing opportunities should include recognition of these aspects of the HIV epidemiology in the UK.

Prevention programmes are often targeted at younger populations and attention needs to be paid to opportunities to include older age groups in prevention campaigns, and the optimal approaches for ensuring older people have equitable access to prevention technologies.

### Person-centred care

It is important to recognise the differences in both the requirements and access to resources necessary for optimum self-management for those in an older age group. The intersection between issues of HIV and ageing may be critical in understanding barriers and enablers for access to quality health and social care, for example, access to residential care or menopause support services, or the geographical provision of HIV-specific services.

Peer support may be particularly important for those diagnosed in older age, as many people will have had no previous exposure to people living with HIV or HIV-related issues. This may be crucial for engagement and retention in care. Peer support needs for those living long term and ageing with HIV will differ from other groups, as issues such as historic stigma and discrimination, community-level loss and survivor guilt may play out quite differently.

It is important to ensure that provision of sources of support and information are relevant and acceptable – not all older adults will be as familiar with online resources as younger people.

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## HIV outpatient care and treatment

Outpatient care needs to incorporate and integrate best quality HIV care and optimal age-related screening and treatment in a manner that does not overwhelm either the patients or the service providers. Proactive screening for and identification of potential comorbidities according to national guidelines (e.g. cardiovascular risk, osteoporosis, diabetes, breast and prostate cancer; see Standard 4b), encouraging smoking cessation, and facilitating access to active lifestyles will be important for people who are ageing with HIV, but it is essential that this does not lead to a hyper-medicalisation of people living with HIV.

## Complex HIV care

There is considerable complexity around comorbidities and their relationship to ageing, particularly in the areas of cardiovascular disease, osteoporosis, menopause and dementia. This is an area where there is significant emerging knowledge.

Where possible the involvement of a geriatrician with HIV knowledge will strengthen service provision for this population. This may be achieved through co-specialty clinics, mentoring schemes or identified experts for the provision of advice and guidance.

There may be more need for multidisciplinary services involving other specialties and primary care to reduce the number of clinic visits and lessen potential for harm, such as HIV pharmacists, older age pharmacists, physiotherapy and occupational therapy. Supplementary tailored health programmes, for example around exercise, may be of increased importance for this population.

In direct clinical terms, attention needs to be paid to drug-drug interactions as we learn more about the possible co-effects of HIV medications and medications used in ageing-related health conditions. It may be important to tailor ART to co-medications including menopause hormone therapy where possible. There may be a need to actively encourage early ART uptake among those diagnosed with HIV in older age, as this may be crucial in reducing morbidity and mortality.

Among those living long term and ageing with HIV, there is a need to recognise that long and complex treatment history may have significant consequences for both health and well-being. In particular, the experience of suboptimal treatment may be implicated in both higher levels of treatment optimism and treatment scepticism. Concerns about remaining treatment options may have implications for treatment switching.

In addition, consideration should be made for the use of designated care coordinators where possible for those experiencing complex care issues, particularly where care is across multiple health and social care service provision.

## Sexual and reproductive health

It is important to take opportunities to discuss sexual activity and health in older people. This is particularly so in primary care, since older adults may be less willing to access sexual health services. Older adults are less likely to use condoms where there are no concerns



about pregnancy and may have come out of a long-term relationship in which condoms were not used. However, perimenopausal women may still be at risk of pregnancy so adequate contraception is important for this group.

As with other groups, all sexually active older people should be made aware of, and have access to, a tailored and comprehensive package of HIV prevention options.

## Psychological care

The core issues discussed in the psychological care standard apply equally to populations of older people living with HIV. There are particularities for the two broad groups identified - those ageing with HIV and those diagnosed in older age - that should be considered when identifying best practice in the provision of psychological care. Considerations for those living long term with HIV may include the experience of multiple loss over many years, the cumulative effects of community-level stigma and discrimination, differing reference points for self-assessment of health and well-being (e.g. having been near to death), and a history of activist engagement with HIV. Issues for those diagnosed in older age may include familiarity with HIV issues, terminology and services, differences in peer and family understandings of HIV, and the primacy of other health concerns.

## Palliative care

Issues associated with palliative care may be particularly acute for both those ageing with HIV and those diagnosed at an older age. For those living long term and ageing with HIV, there may be particular sensitivities around death and dying arising from experiences of profound ill health and from community-level loss. Services referring to and offering palliative care services need to be cognisant of the complex pathways people may have in relation to their health and life expectancy.

## Developing and maintaining excellent care

There is an ongoing need to offer training and professional development in management of comorbidities (HIV, primary and secondary care providers), particularly as they relate to ageing with HIV.

# 7d. Palliative care

*Palliative care is a core component of any health service, ensuring that we optimise quality of life and relieve distress in the face of serious, advanced illness. There is never 'nothing we can do' - palliative care ensures that the individual and their family are supported, receive appropriate care that meets their needs and preferences, and do not experience unnecessary suffering.*

## Rationale

In the UK, mortality is significantly higher among people living with HIV compared to the general population for all causes. Survival is worse for people living with HIV diagnosed

with cancer; non-AIDS cancer is now the leading non-AIDS cause of death among people living with HIV, and survival is worse after myocardial infarction compared to people not living with HIV. Despite this ongoing need to ensure that the focus on high-quality care for people living with HIV continues to the end of life, it has received relatively little attention since the availability of ART. However, ageing with HIV and the increase in serious comorbidity requires us to ensure that good-quality care continues throughout the life course.

Palliative care is defined as ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’ [150]. Palliative care seeks to relieve distress for the patient, and for those around them. It can be delivered alongside potentially curative treatment, and should be initiated as early as possible for people who have life-threatening disease.

Recognising the ‘end of life’ is difficult and is usually understood to be the last 12 months of life. Palliative care teams may provide specialist palliative care for those with complex pain or other symptoms or for management of complex conversations and decision-making. Generalist palliative care should be provided by all healthcare professionals.

Palliative care is highly effective at managing problems such as pain and other symptoms. Early palliative care (i.e. not just at the very end of life) can improve patient well-being, and save costs for the health system (as it prevents people being admitted to hospital unnecessarily, and enables people to be cared for and to die at home should they wish) - it also can help people to live longer by helping them to choose not to have distressing treatments that may not add to the quality of their life.

Access to palliative care is a human right. People with life-threatening illness should expect to have access to palliative care to relieve unnecessary distress. For people living with HIV who are facing the end of their lives, access to good palliative care is crucial to help them plan the care they want. Although access to ART has greatly increased life expectancy for people living with HIV, it is essential that we continue to provide the skills of palliative care to those who may face life-threatening illnesses such as cancer, heart and kidney failure, those whose HIV is not responding to treatment, or for those ageing with HIV who need good end-of-life care. Although most people would choose to know about their poor prognosis and to die at home, people living with HIV are more likely to die in hospital than people dying from other conditions such as cancer. This reflects a number of barriers to palliative care for people living with HIV that must be overcome.

**HIV treatment has improved so much that the focus has shifted away from end of life care. This standard is crucial to guide professionals and patients when the focus changes.**

*Sarah Cox, Consultant and Lead Physician in Palliative Care  
Chelsea and Westminster NHS Foundation Trust*

Good person-centred care should take a ‘whole-person’ approach, which includes an understanding of sexuality and culture. Gay and bisexual men are disproportionately affected by HIV, and their end-of-life care should be in line with their preferences for involvement of family and others, using appropriate language, and specialist palliative

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care services should follow existing recommendations to provide MSM with appropriate care. Good palliative care may also improve the bereavement outcomes of their significant others. For patients of African heritage, cultural differences in the acceptance and the patient's interpretation of pain should be taken into account to avoid under-treatment. In addition, people with comorbid substance use may have specific and complex social care needs that would benefit from the detailed social history taking and care planning that is the hallmark of palliative care. However, evidence suggests that people living with HIV who use drugs have historically had poorer access to palliative care.

Given the additional aspects of stigma and confidentiality for people living with HIV, information sharing should be conducted carefully and in line with patient preferences. As palliative care aims to support families and other important people in the patient's life, information sharing should be directed by the patient.

Although other standards in this document are relevant to palliative care (e.g. psychological support), palliative care cannot be achieved unless a whole-person approach with multidimensional assessment and care (i.e. physical, psychological, social and spiritual) is conducted. This multidimensional approach with careful attention to pain and symptom control differentiates palliative from supportive care. Given the high prevalence and burden of pain (including neuropathic pain) and other symptoms among people living with HIV who are accessing treatment, the detailed assessment and management of these problems should be stressed. Person-centred outcome measures such as the Palliative Care Outcome Scale (iPOS) are routinely used across the UK to inform assessment and monitoring or patients' and families' symptoms and concerns. In primary care it is currently more common to use the Gold Standards Framework ([www.goldstandardsframework.org.uk/](http://www.goldstandardsframework.org.uk/)) or the Royal College of General Practitioners Palliative Care and End of Life Toolkit ([www.rcgp.org.uk/clinical-and-research/resources/toolkits/palliative-and-end-of-life-care-toolkit.aspx](http://www.rcgp.org.uk/clinical-and-research/resources/toolkits/palliative-and-end-of-life-care-toolkit.aspx)).

**Now is the time to look forward and plan how to die well.  
It should not only be with dignity and respect, but with  
self-knowledge too.**

*Roy Trelvelion, HIV i-Base*

The Mental Capacity Act 2005, in England and Wales allows people to express their preferences for care and treatment, and to appoint a trusted person to make a decision on their behalf should they lack capacity in the future (see references for further information on incapacity and mental capacity). In Scotland, the Adults with Incapacity Act (Scotland) 2000 ([www.gov.scot/Publications/2008/03/25120154/1](http://www.gov.scot/Publications/2008/03/25120154/1)) and the Mental Health Act (Scotland) 2015 ([www.gov.scot/Topics/Health/Services/Mental-Health/Law/2015Act-provisions](http://www.gov.scot/Topics/Health/Services/Mental-Health/Law/2015Act-provisions)) should be followed. In Northern Ireland, the Mental Capacity Act 2016 (Northern Ireland) applies ([www.legislation.gov.uk/nia/2016/18/contents/enacted](http://www.legislation.gov.uk/nia/2016/18/contents/enacted)).

## Quality statements

### Communication

- Information should be shared in a manner and at a pace in line with patient preference.
- Communication should be recognised as an ongoing process as needs, preferences and priorities change.
- The specific information that has been shared should be recorded to ensure the whole team understand patient insight.
- Clarity should be sought from the patient on confidentiality and sharing of information.

### Timeliness

- Clinical uncertainty should be recognised (i.e. treatment, prognosis or recovery are complex or unpredictable).
- Palliative care should be included as part of whole-patient management from the point of diagnosis of a life-limiting condition.

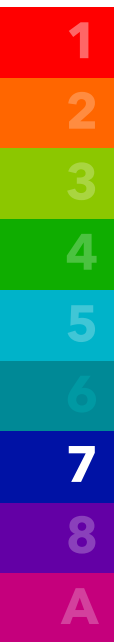
### Management

- All clinical staff should be able to provide basic assessment and delivery with respect to palliative care.
- Ongoing, holistic, person-centred assessment care planning is required.
- Relationships should exist between HIV teams and specialist palliative care teams who can manage apparently refractory problems.
- Complex pain cases should be referred to a pain clinic.
- Assessment and monitoring of person-centred outcomes should underpin routine practice.
- Pain and symptom control should be at the heart of care plans and delivery.
- Palliative rehabilitation should be provided to optimise engagement, function and performance.
- Care should address the symptoms and concerns of both the patient and their significant others.

### Planning

- Practice will require plans to be in place for exacerbations, palliative care emergencies and when an unplanned admission is a potential risk against individual wishes.
- Teams should establish preferences for end of life and should offer advance care plans and advance directives, which should be reviewed and be readily available to all team members.
- There should be regular revisiting of wishes as this will be required as disease progresses.
- Clarity and documentation in the medical record is needed on who should be involved in care planning and provision in the case of reduced capacity.





- Discussion and information about death and dying should be offered at appropriate times at a pace that is in line with patient preference.
- Death certification should follow GMC guidance which states that HIV (as a serious communicable disease) must be disclosed on the death certificate if it contributed to the death ([www.gmc-uk.org/guidance/ethical\\_guidance/30625.asp](http://www.gmc-uk.org/guidance/ethical_guidance/30625.asp)).

## Measurable and auditable outcomes

- Proportion of people living with HIV with life-limiting illness being managed in an inpatient or specialised care setting with documented evidence of implementation of the Integrated Palliative Outcome Scale at least weekly (more frequently in deteriorating patients) to monitor patient-centred outcomes (either self-report or proxy-report); available at [www.pos-pal.org](http://www.pos-pal.org) (target: 90%).
- Proportion of patients living with HIV with life-limiting illness with documented evidence of having had a conversation regarding prognosis (target: 90%).
- Proportion of patients living with HIV with life-limiting illness with documented evidence of patient preferences for end-of-life care (target: 90%).
- Proportion of patients living with HIV with life-limiting illness with documented advance care plan/advance directive (target: 90%).
- Proportion of patients living with HIV with life-limiting illness who achieved preferred place of care for majority of the last 90 days (target: 90%).
- Proportion of patients living with HIV with life-limiting illness with documented clear and agreed plans for emergencies and admissions (target: 90%).

References: 33, 145-170





# 8. Developing and maintaining excellent care

## 8a. Knowledge and training

*People living with HIV should receive care overseen by a consultant physician specialist in HIV and provided by practitioners with appropriate competencies within suitable and recognised governance and management structures. It is also important that other non-specialist health and social care workers have core HIV knowledge.*

### Rationale

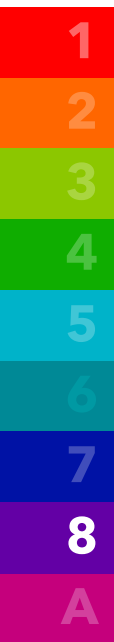
Ensuring patient safety and delivering care of the highest quality are fundamental responsibilities of health and social care providers. The clinical care of people who are living with HIV is complex, requiring management of issues ranging from immunosuppression through to psychological health. There is a two-way interplay between HIV and many other health conditions. For these reasons, people living with HIV should expect to receive care overseen by a consultant physician who has specialist knowledge and skills in HIV medicine.

The complexity of HIV makes it essential that people are managed by a multidisciplinary team (MDT) working alongside relevant specialties. It is important that care is provided within a suitable and recognised organisational structure for appropriate accountability and essential that continued teaching, training and sharing of best practice is in place.

Not all the clinical services will be available within the local team. It is important that network arrangements including with those with community services are in place. Timely referral should be made to practitioners with the appropriate knowledge and skills.

In order that there is timely access to high-quality care it is also essential that non-specialist health and social care workers have accurate general knowledge about HIV and that they





build skills and develop attitudes that further advance this quality. This will help reduce HIV stigma that still exists within the health service. Such training should also include the principles and practice of confidentiality, data protection, equality and diversity.

## Quality statements

- HIV remains a stigmatising condition that affects people who often are already vulnerable. For example, because of single or combined factors relating to gender, sexuality, age, race, income, education, drug and/or alcohol use or other medical and social history. All staff in HIV services should have appropriate training regarding the diversity of affected communities and important social and health influences.
- Ensuring healthcare workers have core knowledge about HIV is a key element in combating stigma within the NHS and it is recommended this teaching is included in the mandatory training undertaken by all employees.
- Ensuring this core HIV knowledge is also important for other staff working with vulnerable and/or affected groups including social care providers.
- All healthcare professionals engaged with provision of specialist HIV services are required to maintain their competencies to encompass the most up-to-date national guidelines, recommendations and advances in care.
- Healthcare professionals should be supported to disseminate their expertise through teaching, training and sharing of best practice.
- Where healthcare professionals are undertaking a specialist HIV role it is important that HIV care is specifically addressed in continuing professional development and appraisal.
- Curricula are an important structural component of training. Meaningful involvement of people living with HIV in the development of these, particularly specialist training curricula, is recommended.

## Teams

### Medical team

### HIV specialists

The HIV competencies required for genitourinary medicine (GUM) specialty trainees to complete training are outlined in the syllabus of the Joint Royal Colleges Postgraduate Training Board (JRCPTB) GUM curriculum (2016) ([www.jrcptb.org.uk](http://www.jrcptb.org.uk)). For infectious disease (ID) specialists, the 2014 ID curriculum ([www.jrcptb.org.uk](http://www.jrcptb.org.uk)) details the competencies required to manage patients with HIV.

The Diplomas of GU medicine (Dip GU Med) and HIV Medicine (Dip HIV Med) are compulsory for GUM trainees to complete specialist training and to enter the General Medical Council register of specialists. The Dip HIV Med exam is also highly recommended for ID trainees although it is not compulsory. In order for ID trainees to complete specialist training it is required that they pass the Fellow of the Royal College of Pathology (FRCPath) Part 1 and Combined Infection Certificate Examination (CICE) which includes assessment of HIV medicine. The details of this exam, can be viewed at [www.rcpath.org](http://www.rcpath.org)



Personal development plans should include educational or training activities that relate directly to HIV care. This should include either attendance at a national or international meeting at least once every 2 years, or alternatively online access to conference proceedings and/or attendance or online access to conference feedback meetings. For specialists undertaking inpatient care of people living with HIV, or who undertake care of people with complex comorbidities or co-infections, it is critical that the appraisal process includes these areas and also addresses the need to keep up to date in general medicine. Suitable CPD-approved general medicine courses are widely available.

### Non-HIV specialists, general practitioners and other community-based practitioners

People living with HIV access all areas of the health service and it is critical that all doctors (both specialists and general practitioners) have a core knowledge of HIV including the following:

- Who and how to test for HIV including screening, opt-out testing, and testing those with HIV-indicator conditions
- Prognosis of people living with HIV in the ART era
- HIV transmission - including that having an undetectable viral load prevents transmission
- Role of ART in preventing and reducing ill health
- Management of relevant (non-HIV related) conditions in people living with HIV
- Importance of drug-drug interactions (DDIs) between ART and other agents and how to access the information on DDIs
- High incidence of anxiety and depression in people living with HIV

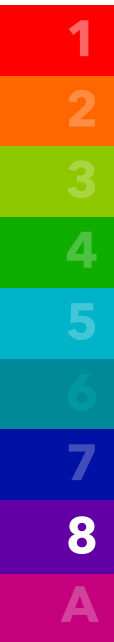
### Nursing team

Specialist HIV nursing should be provided by registered nurses, within primary and secondary care with support from health support workers as appropriate. The knowledge and skills required for specialist HIV nursing care are outlined in the National HIV Nurses Association (NHIVNA) 'National HIV Nursing Competencies' (October 2013) and nurses working in advance practice are supported by 'Advanced Nursing Practice in HIV care: Guidelines for Nurses, Doctors, Service Providers and Commissioners' (August 2016).

Registered nurses should demonstrate competence to the appropriate level in the four core areas:

- assessment of health and well-being
- management of ART
- health promotion
- working in partnerships

and additionally, where relevant, the specialist competencies for outpatients, inpatients, adolescents and research. The competency levels required relate not only to job banding and job specification but also the level of specialist HIV care that is required. This level will differ for an HIV specialist nurse in an HIV clinical area compared to a generalist nurse providing some HIV care within their role (e.g. a district nurse).



The process of assessment of competence (based on the NHIVNA competency framework) will be locally determined and should be multi-faceted including (e.g. direct observation and reflective practice). Learning opportunities for specialist nurses are: NHIVNA online training and CPD articles ([www.nhivna.org](http://www.nhivna.org)), NHIVNA conference and study days, some HIV-specific modules at diploma and degree level. Nurses working in advanced practice should undertake non-medical prescribing and preferably undertake master's-level education, although this is only locally determined by health trusts.

### *Competency to prescribe ART*

Nurse independent prescribers are nurses who have successfully completed an NMC independent nurse prescribing course. Those who have successfully completed the supplementary part of the prescribing course are also able to prescribe against a clinical management plan.

### **Pharmacy team**

Specialist pharmacy support should be provided by registered pharmacists and pharmacy technicians who are competent in the pharmaceutical care issues of people living with HIV. For example, drug-drug interaction management of ART and other medicines including over-the-counter, herbal and recreational drugs. They should have current appropriate knowledge and skills and be appraised annually.

### *Competency to prescribe ART*

Pharmacists carrying out advanced practice roles such as independent prescribing should fulfil the requirements of the Royal Pharmaceutical Society Competency Framework for all Prescribers. They should have shared access to the patient care record and prescribe within their scope of practice according to local and national guidelines.

### **Peer-support team**

Peer support can be delivered by paid staff and volunteers who are living with HIV in both one-to-one and group settings. There are many approaches to providing peer support, this can be informal or a formal structured approach such as peer mentoring. These Standards are primarily concerned with the delivery of structured support as set out in the 'National Standards of Peer Support in HIV' (2017).

Peer support works best when facilitated by trained peers from the community they support. The breadth of knowledge and skills involved in providing peer support means it is important that the people providing it should have access to structured training, linked to a professional qualification, where appropriate and possible. Core competencies should include knowledge and understanding of HIV and treatments, ability to recognise and work with diversity, effective listening and communication skills, understanding of confidentiality and safeguarding for vulnerable adults. Organisations or groups providing peer support should provide peer supporters with regular structured support and supervision, as well as ongoing professional development.

### Rehabilitation team

Physiotherapists, occupational therapists and other rehabilitation specialists should be registered with the Health and Care Professionals Council (HCPC). Physiotherapists working in any setting should have advanced skills in neurological, respiratory and musculoskeletal practice, while occupational therapists and speech and language therapists should have advanced skills in neurological practice and, in particular, neurocognitive assessment and treatment.

### Dietetics team

Specialist dietetic input should be provided by registered dietitians and dietetic assistants competent in the dietetic care of people living with HIV. The knowledge and skills required for specialist HIV dietetic care are outlined in the Dietitians in HIV/AIDS (DHIVA) 'Dietetic Competency Framework'. They should demonstrate competence to the level appropriate for the level of specialist HIV care that is required, reflected in their job banding and job specification. The process of assessment of competence will be locally determined and should be part of appraisal, objective-setting and personal development planning. Dietitians are required by the HCPC to maintain an accurate record of their CPD activities.

## Measurable and auditable outcomes

- Proportion of completed appraisals that contain documented evidence of HIV-related CPD (target: 95%).
- Proportion of provider organisations that include key HIV information within mandatory training.
- Proportion of trainees and students working within an HIV service (all professions) with a named supervisor (target: 90%).
- Proportion of trainees and students (all professions) within an HIV service with documented evidence of supervision of safe and competent HIV practice (target: 90%).

**References:** 6, 171-175

## 8b. Monitoring and audit, research and commissioning

*Services should participate in national and local audits, reviews and quality improvement and share results with service users and commissioners.*

*Service providers should embed mortality and morbidity reviews into governance structures to enable learning from serious incidents, deaths and late diagnoses.*

*People living with HIV should expect to be informed of opportunities to take part in ethically approved research and public health activities that are relevant to their health and care.*

### Rationale

As part of delivering high-quality, innovative and safe services, HIV service providers routinely engage in quality improvement, clinical audit, service reviews and the evaluation of serious incidents and deaths through mortality and morbidity reviews. The outcomes of these exercises are critical to the provision of patient care since they are used to assess the quality of care received by patients; inform the commissioning of services and development of clinical guidelines; and drive clinical research.

#### Monitoring and audit

Clinical audit and service evaluation are key drivers for improving the quality of HIV care by checking whether current best practice is being followed and identifying where improvements should be made.

Individual review and investigation is warranted for serious incidents involving major consequences for patients, families or carers and/or substantial potential for learning, including some cases of late HIV diagnosis. Review of care provided to people who die can be revealing and should include all deaths among people known to have HIV.

#### Research

Creating new knowledge and finding the most appropriate ways to use existing knowledge are vital for progress in the HIV field. Research and innovation underpin the understanding and response to HIV, the way treatments are provided to people living with HIV, and the improvement of prevention, treatment and outcomes for people living with HIV.

#### Commissioning

People living with HIV should be cared for by services that are commissioned based on robust and appropriate needs assessments. Service delivery and quality assurance should be in line with and monitored against relevant local and national service specifications. Services and commissioners should work together to ensure that the data required to plan and commission services are appropriately shared. The complexity of HIV, the range of care services required, and the number of commissioning bodies involved mean that commissioners should work together to plan provision across the entire care pathway. Commissioners of services used by people living with HIV should have formally established processes in place to ensure the active involvement of people living with HIV and vulnerable population groups



## Quality statements

- Providers of NHS HIV care (which may include independent providers) should take part in relevant national and local audit, quality improvement projects, service reviews and relevant research studies.
- Providers of NHS HIV care should review deaths and serious incidents, which may include late HIV diagnoses, in accordance with current policy frameworks (see Standard 4a).
- HIV services should have procedures to alert people to appropriate opportunities for them to join in ethically approved research programmes and clinical trials if they so wish.

## Measurable and auditable outcomes

- Proportion of services contributing to national HIV audits (target: 95%).
- Proportion of services with evidence of undertaking local audits related to the delivery of HIV care (target: 95%).
- Proportion of services with evidence of undertaking local quality improvement activities in response to outcomes of HIV-related audit and/or review (target: 95%).
- Proportion of services with documented evidence of active engagement in research that is appropriate to their patient population or awareness of HIV-relevant research within the NIHR research portfolio and elsewhere, and mechanisms in place to alert patients to relevant research programmes and how to access them (target: 95%).

References: 176–179

# 8c. Public health surveillance, confidentiality and information governance

*Services delivering HIV care should actively provide data to national surveillance programmes.*

*People living with HIV should be informed and given choices about how their personal clinical information is shared with clinicians involved in their overall care outside HIV services.*

*All patient-related information, whether clinical, pseudonymised or anonymous, should be held securely in compliance with information governance standards and national legislation.*

## Rationale

Service providers routinely collect data relating to the care received by people living with and affected by HIV. These data are critical to the provision of patient care since they are used to inform the public health response to HIV, including evaluation of prevention initiatives, and further inform the commissioning of services and development of clinical guidelines. Use of identifiable, anonymised and pseudonymised information is bound by strict information governance policies and confidentiality rules.

## Public Health Surveillance

Data collected locally in England, Wales and Northern Ireland are sent securely to Public Health England (PHE), and in Scotland to Health Protection Scotland (HPS) for surveillance purposes. These data are used to monitor the number of people newly diagnosed and living with HIV, access to HIV care and treatment and key outcomes including virological undetectability on ART, and to target prevention initiatives. The data provide national and local outputs such as the Public Health Outcomes Framework indicator for reducing late HIV diagnosis and NHS England's HIV Quality Dashboard, and are used to plan and commission appropriate services for people living with HIV.

Public Health data are also linked to other public health and clinical datasets to monitor co-infections and other indicators (e.g. transmitted drug resistance).

## Confidentiality

The duty of confidentiality of personal medical information is protected by law in the UK. This means that all personal medical information, whether held on paper, computer, visually or audio recorded, or held in the memory of the professional, must not normally be disclosed without the consent of the patient.

Patient consent, implied or explicit, is required for any handling of personal confidential information. This includes any data that can potentially be linked to the individual via, for example name (including Soundex code), date of birth, address, post code of residence, clinic or national ID number. Data without personal identifiers is anonymous and is not personal information. Data with names, dates of birth and addresses removed is called pseudonymised data and could still be personal information if it is possible to link the data back to the patient.

The Health and Social Care Information Centre (HSCIC), now known as NHS Digital, defines consent as 'the approval or agreement for something to happen after consideration'. Explicit consent can be given in writing, orally or through other forms of communication such as signing. Implied consent refers to instances where the consent can be assumed without the patient making any positive action. HSCIC refers to a 'care team' stating that information must not leak outside this team but needs to be shared within it in order to provide a seamless, integrated service (e.g. doctors and nurses working on a ward caring for a patient or referrals from an HIV team or GP to another speciality).

Consent should be explicitly sought where information is being disclosed to third parties (e.g. insurance companies, employers). Consent for information sharing, implied or explicit, is only valid if the patient understands what data are stored and who can access their information.

Patients can explicitly refuse consent to share information with teams that provide direct care and this decision should be respected. If the personal confidential information, such as HIV-positive status, is considered by the healthcare professional to be essential for safe provision of direct care, they should explain to the patient that not providing this information may compromise their care. In exceptional circumstances, withholding consent to sharing information may amount to refusal of care.

There are some situations where disclosure is required without an explicit requirement for patient consent such as legal obligation to disclose, for example a court order, or if the clinician believes that there is an overriding public interest to do so such as to aid the prevention, detection or prosecution of serious crime or prevent the spread or reduce risk from serious communicable diseases. These situations are exceptional, and consent should



still be sought where possible. In situations of partner notification of HIV, disclosing a person's HIV status without their consent is a last resort with many factors taken into account including harm to the index patient if disclosure occurs, risk of non-disclosure to the partner's or others health and well-being.

### Information governance

At all levels, identifiable or potentially identifiable data must be held securely with access strictly restricted to trained data managers and clinical/epidemiological/research staff, and in compliance with information governance standards and the relevant legislation.

For national surveillance data, all staff within the national public health agency have a legal duty to keep patient information confidential. All those who have access to data are bound by strict data security guidelines.

In order to ensure data are accurate, limited patient identifiers are collected for epidemiological surveillance purposes. These data do not include names and addresses of people living with HIV (this information is only retained by the local service providers with which individuals are in direct contact). Without these limited identifiers, the number of people living with HIV would be overestimated as people living with HIV can, and frequently do, access any HIV service across the UK. This information is also used to check the accuracy of data and to correct any errors. In addition, these data are also used to monitor longer-term outcomes of people living with HIV, through linking data between years. Linkage to other secure public health and clinical datasets enables the monitoring of key outputs such as late HIV diagnoses and treatment coverage, and allows service needs to be planned accordingly. Secondary analyses of these data may also be conducted for surveillance and research after all patient identifiers have been removed.

### Digital records and national patient ID numbers

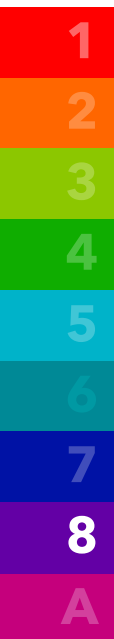
Electronic/digital patient management systems may involve several electronic systems for various functions (e.g. appointments management, case notes, management investigations, prescribing and dispensing of drugs, and communications management). The individual patients are linked on these systems using a unique identifier, usually a clinic ID. National patient ID numbers such as the NHS number in England, Wales and the Isle of Man, Community Hospital Index (CHI) number in Scotland, and the Health and Care number in Northern Ireland could be used to link all (primary care and secondary care) care records for a patient. All electronic and web-based systems used in healthcare settings should be compliant with the UK Data Security Centre good practice guidance.

Patients have the right of access to their records under the Data Protection Act and have the right to have factual inaccuracies corrected

Patient-owned data systems are also available as websites and apps. These offer opportunities for recording detailed patient monitoring and activity data but offer challenges for information governance.

## Quality statements

- Providers of HIV services should actively participate in public health surveillance.
- Public health surveillance data should be submitted electronically via a secure web portal within agreed time frames.



- People living with HIV should expect that their health record will be used, in confidence, by a health professional or by a person who has the same duty of confidentiality. Only data that are useful for surveillance, commissioning, monitoring of care or research will be collected and the information will not be used for any other purpose.
- All data must be held securely and according to information governance standards and the law.
- HIV service providers should have robust information systems with dedicated data-management staff to ensure accurate, complete and up-to-date information.
- HIV services should have clear mechanisms for ensuring data quality - ideally direct extraction from an electronic clinical record system, which is accurately maintained in real time.
- HIV services should follow robust information governance and confidentiality policies. Implied patient consent for sharing personal identifiable clinical information outside HIV services with other professionals involved in the care of the individual patient may be assumed.

## Measurable and auditable outcomes

Evidence from national public health agencies (e.g. Public Health England or Health Protection Scotland) that services have provided:

- Required data for all patients seen for care in the relevant reporting period
- Data within agreed time frames
- Data should be complete (mandatory fields should be 90% complete) and consistent
- Evidence from national public health agencies (e.g. Public Health England or Health Protection Scotland) that information has been used to:
  - Produce national and local public health outputs
  - Inform commissioning
  - Audit national standards
  - Proportion of service providers with documented evidence that they have policies in place to protect the confidentiality of their patients and actively seek consent for information sharing of personal clinical data where relevant/applicable (target: 95%).

**References:** 1, 180-187

# Appendix 1

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# Appendix 2

## Additional resources

### 1b. Prevention

#### Prevention Access Campaign's Consensus Statement

The following statement has been endorsed by over 600 organizations from 75 countries:

**People living with HIV on ART with an undetectable viral load in their blood have a negligible risk of sexual transmission of HIV. Depending on the drugs employed it may take as long as six months for the viral load to become undetectable. Continued and reliable HIV suppression requires selection of appropriate agents and excellent adherence to treatment. HIV viral suppression should be monitored to assure both personal health and public health benefits.**

NOTE: An undetectable HIV viral load only prevents HIV transmission to sexual partners. Condoms also help prevent HIV transmission as well as other STIs and pregnancy. The choice of HIV prevention method may be different depending upon a person's sexual practices, circumstances and relationships. For instance, if someone is having sex with multiple partners or in a non-monogamous relationship, they might consider using condoms to prevent other STIs.

**'NEGLIGIBLE' = so small or unimportant as to be not worth considering; insignificant.**

Since the statement was first issued in July 2016, a further Editor's note was published in January 2018:

The term 'negligible' is not effective in public health messaging to describe the risk of HIV sexual transmission when a person with HIV has an undetectable viral load and is taking ART as prescribed. 'Negligible' is often misconstrued as still a risk to take into consideration in sexual and reproductive health decisions. Please see the messaging guide with examples of the words used in public health messaging to convey the risk including 'effectively no risk', 'cannot transmit' and 'do not transmit.' It is imperative that language instills confidence rather promote unnecessary fear about sexual transmission when a person with HIV has an undetectable viral load and is taking ART as prescribed.

The Consensus Statement along with a messaging primer can be found in full at: [www.preventionaccess.org/consensus](http://www.preventionaccess.org/consensus).



1

## 7a. Young adults and adolescents living with HIV

Further National Transitional Care Guidance

National Institute for Health and Care Excellence. Transition from children's to adults' services for young people using health or social care services. NICE guidelines (NG43). 2016. Available at: [www.nice.org.uk/guidance/ng43](http://www.nice.org.uk/guidance/ng43)

Royal College of Paediatrics and Child Health. The Intercollegiate Working Party on Adolescent Health. Bridging the gaps: health care for adolescents. 2003. Available at: [www.rcpch.ac.uk/publications](http://www.rcpch.ac.uk/publications)

You're Welcome quality criteria: Making health services young people friendly. 2007. [www.dh.gov.uk](http://www.dh.gov.uk)

CHIVA guidance on transition for adolescents living with HIV. Available at: [www.chiva.org.uk/files/2814/8587/2242/CHIVA\\_Transition\\_Guidelines2017.pdf](http://www.chiva.org.uk/files/2814/8587/2242/CHIVA_Transition_Guidelines2017.pdf)

A

## 7d. Palliative care

Watson M, Armstrong P, Back I et al. Palliative Adult Network Guidelines. 4th edn. 2016.

Clinical Guide on Supportive and Palliative Care for People with HIV/AIDS. 2003. Available at: [careacttarget.org/library/clinical-guide-supportive-and-palliative-care-people-hiv aids](http://careacttarget.org/library/clinical-guide-supportive-and-palliative-care-people-hiv aids)

Palliative care Outcome Scale. Available at: [www.pos-pal.org](http://www.pos-pal.org)

Priorities for care part of new approach to care for dying people. 2014. Available at: [www.cqc.org.uk/news/stories/priorities-care-part-new-approach-care-dying-people](http://www.cqc.org.uk/news/stories/priorities-care-part-new-approach-care-dying-people)

End of life care strategy: promoting high quality care for adults at the end of their life. 2008 [www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life](http://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life)

Ambitions for palliative and end of life care: route to success. Available at: [endoflifecareambitions.org.uk/route-to-success/](http://endoflifecareambitions.org.uk/route-to-success/)

ACCESSCare (UK recommendations for palliative and end-of-life care for LGBT people). Available at: [www.kcl.ac.uk/nursing/departments/cicelysaunders/research/living/access/index.aspx](http://www.kcl.ac.uk/nursing/departments/cicelysaunders/research/living/access/index.aspx)

The Mental Capacity Act 2005. Available at: [www.nhs.uk/conditions/social-care-and-support/mental-capacity/](http://www.nhs.uk/conditions/social-care-and-support/mental-capacity/)

# Appendix 3

## Glossary of terms and abbreviations

**Adherence:** Adherence to medicines is defined as the extent to which the patient's action matches the agreed recommendations. Non-adherence may limit the benefits of medicines, resulting in lack of improvement, or deterioration, in health and the emergence of drug resistant strains of HIV.

**Adherence support:** Mechanisms and interventions that help patients match the agreed recommendations, allowing them to take the correct dose of the correct drug at the correct time.

**AIDS (acquired Immunodeficiency syndrome):** AIDS is a clinical syndrome, characterised by an increased susceptibility to a number of infectious and malignant conditions, which is the result of damage to the immune system caused by HIV.

**Antiretroviral therapy (ART, ARVs):** Drugs, usually taken in combination with one another, that suppress the activity of HIV by inhibiting viral replication.

**BASHH:** British Association for Sexual Health and HIV ([www.bashh.org](http://www.bashh.org)).

**BHIVA:** British HIV Association ([www.bhiva.org](http://www.bhiva.org)).

**CD4 cells:** The class of white blood cells known as CD4 T-helper lymphocytes, which are the target cells for HIV and subsequent damage.

**CD4 count:** The number of CD4 T-helper lymphocytes in the blood. Someone without HIV normally has a count between 500 and 1200 cells/mm<sup>3</sup>.

**Chemsex:** Sex between men under the influence of drugs (typically methamphetamine, mephedrone, GHB/GBL) taken immediately before and/or during a sex session to sustain, enhance, disinhibit or facilitate the experience and performance.

**CHI:** Community Hospital Index number (Scotland)

**CHIVA:** Children's HIV Association ([www.chiva.org](http://www.chiva.org))

**Clinical indicator condition:** A specific clinical condition which is associated with HIV and in which HIV therefore enters the differential diagnosis.

**Commissioning:** The process of planning, agreeing and monitoring services

**Continuing Professional Development (CPD):** An ongoing commitment to learning in various forms, which maintains knowledge and skills, and which enhances professional standards of work. This is an obligatory component of most professions.

**CQUIN:** Commissioning for quality and innovation national goals.

**CSE:** Child sexual exploitation

1

**Designated:** A specified place or person that is identified for a certain purpose or responsibility.

2

**DoH:** Department of Health.

3

**DHIVA:** Dietitians working in HIV/AIDS.

4

**Drug interaction (drug-drug interaction or DDI):** A situation in which a substance (often another drug) affects the activity of a drug, i.e. the effects of the drug may be increased or decreased, or a new effect may occur that neither agent produces when taken on its own.

5

6

**Drug resistance:** The ability of HIV to overcome the drugs used in its treatment. Other terms include class resistance and multi-drug resistance. Class resistance refers to a strain of HIV that shows evidence of resistance to one class of drug (e.g. NRTIs, NNRTIs or PIs). Multi-drug resistance usually implies resistance to multiple classes of drugs.

7

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**FRRSH:** Faculty of Sexual and Reproductive Healthcare ([www.fsrh.org](http://www.fsrh.org)).

A

**GMC:** General Medical Council ([www.gmc-uk.org](http://www.gmc-uk.org)).

1

**GU or GUM:** Genitourinary medicine. Medical specialty relating to the diagnosis and management of sexually transmitted infections (including HIV) and other genital conditions in men and women.

2

3

**HCPC:** Health and Care Professions Council ([www.hcpc-uk.co.uk](http://www.hcpc-uk.co.uk)).

4

**HDU:** High-dependency unit.

5

**HPS:** Health Protection Scotland ([www.hps.scot.nhs.uk](http://www.hps.scot.nhs.uk)).

6

**HIV:** Human immunodeficiency virus.

**HIV resistance assay:** An assay to identify the presence of changes within the genetic make-up of HIV which will lead to drug resistance. It is useful in deciding which HIV drugs to use to treat HIV in an individual patient.

**HLA-B\*5701:** HLA-B\*5701 is one of a family of human genes, the human leukocyte antigen (HLA) complex. This particular HLA type is associated with allergic reactions to the drug abacavir.

**ID (infectious diseases):** The branch of medicine that specialises in the diagnosis and management of infectious diseases.

**Immunosuppression:** A reduction in the activity or the effectiveness of the immune system, leaving the individual more susceptible to a range of infections.

**IPV:** Intimate partner violence.

**ITU:** Intensive therapy unit.

**'Late' and 'very late' HIV diagnosis:** A CD4 cell count below 350 cells/mm<sup>3</sup> at time of diagnosis of HIV. Very late diagnosis is either clinical presentation of AIDS at time of HIV diagnosis or a CD4 cell count less than 200 cells/mm<sup>3</sup>.

**LGV:** Lymphogranuloma venereum: a sexually transmitted infection caused by the invasive serovars L1, L2, L2a or L3 of *Chlamydia trachomatis*.

**Morbidity and comorbidity:** The state of being unhealthy and/or having a particular disease. Comorbidity refers to the presence of all the diseases and health problems that may exist in an individual patient, in addition to HIV.

**MDT/multidisciplinary team:** The term 'multidisciplinary team' used in this document refers to a group consisting of representatives from several different professional backgrounds and areas of expertise.

**MSM:** Men who have sex with other men. Refers to any man who has sex with another man, whether he identifies himself as gay, bisexual or heterosexual.

**Network:** A collaboration between service providers to ensure that people living with HIV have equity of access to appropriate care. The network will vary depending on prevalence, cost and complexity of condition. It may involve two local services working together and be based regionally or nationally. The collaboration may involve multiple specialties working together as part of an MDT.

**NHIVNA:** National HIV Nurses Association ([www.nhivna.org](http://www.nhivna.org))

**NIHR:** National Institute for Health Research. An organisation whose aim is improving the health and wealth of the nation through research ([www.nihr.ac.uk](http://www.nihr.ac.uk)).

**NSF:** National Service Framework.

**NSHPC:** National Study of HIV in Pregnancy and Childhood. This is a confidential national (UK and Ireland) reporting scheme for pregnancies in women who are HIV positive, babies born to women who are HIV positive and other children with HIV ([www.ucl.ac.uk/nshpc](http://www.ucl.ac.uk/nshpc)).

**Onward transmission:** When a virus/infection is passed on from one individual to another.

**Opportunistic infection:** An infection that will usually only occur in a person who has a compromised immune system. Their occurrence in the context of HIV infection usually indicates that the person needs to start ART. Many are AIDS-defining.

**p24 antigen:** This is a component of the HIV virus that is one of the earliest markers of HIV. Testing for p24 antigen is used to detect primary HIV infection.

**Post-exposure prophylaxis (PEP):** Immediate HIV therapy (started within 72 hours of exposure), usually given for 4 weeks, following a high-risk HIV exposure. The aim is to reduce the risk of acquiring HIV.

**PHE:** Public Health England ([www.dh.gov.uk/health/tag/public-health-england/](http://www.dh.gov.uk/health/tag/public-health-england/))

**PN:** Partner notification. This is a process whereby the sexual partners of people with a diagnosis of an STI are informed of their exposure to the infection.

**Pre-exposure prophylaxis (PrEP):** Anti-HIV medication taken by people who are HIV negative to lower their risk of acquiring HIV. It usually involves taking drugs on a daily basis.

**Prophylaxis:** Treatment that is given to prevent the occurrence of an infection.

**QIPP:** NHS Quality, Innovation, Productivity and Prevention.



1

**RHIVA:** Rehabilitation in HIV Association ([www.bhiva.org/RHIVA.aspx](http://www.bhiva.org/RHIVA.aspx)).

2

**Stepped-care model:** A model with four essential levels of psychological support provision for people living with HIV, based on levels of need.

3

**STI:** Sexually transmitted infection.

4

**Treatment as prevention (TasP):** An HIV prevention intervention where treating an HIV-positive person with antiretroviral medication is used to reduce the risk of transmission of the virus to a negative partner.

5

6

**Tertiary care:** Specialised consultative care, usually on referral from primary or secondary medical care personnel, by specialists working in a centre that has personnel and facilities for special investigation and treatment.

7

8

**Transition:** The purposeful, planned movement of adolescents and young adults with chronic physical and mental conditions from child-centred to adult-oriented health care systems.

A

1

**TB:** Tuberculosis. An infection due to *Mycobacterium tuberculosis* that is associated with HIV.

2

**Tropism:** HIV tropism refers to the cell type that the human immunodeficiency virus (HIV) infects and in which it replicates.

3

**UNAIDS:** The Joint United Nations Programme on HIV/AIDS ([www.unaids.org](http://www.unaids.org)).

4

**Viral load:** The quantity and activity of HIV in an individual's blood, usually measured by a test that determines the number of copies/mL.

5

6

**Viral rebound:** Confirmed measurable HIV viral load, usually of more than 200 copies/mL, after previously reaching viral suppression on therapy.

**Vertical transmission:** Also known as 'mother-to-child' transmission. The transmission of an infection or other disease from a woman to her child. 'Vertical transmission' is a more inclusive term, and acknowledges the role of the father/male sexual partner.

**Virtual clinic:** Provision of expert advice by a multidisciplinary panel of experts from a specialist treatment centre on the therapeutic treatment options for a patient managed by a clinician located at the same or a different treatment centre via on-line and other ICT-based remote management systems.



# Appendix 4

## Development of Standards and contributors

A Steering Group was convened by BHIVA to include representation from organisations involved in the provision and commissioning of care for people living with HIV together with people living with HIV. Three work streams have led to the development of these Standards:

- Reviewing and updating the content and structure of the 2013 Standards of Care. Input was solicited from the attendees at the BHIVA national conference in April 2017. BHIVA members and UK-CAB were contacted to request input and feedback.
- Drafting the rationale, quality statements and appropriate outcome measures for each standard. Writing Groups (led by a nationally recognised expert in the topic area, nominated by the chairs of the Steering Group) were tasked with drafting the appropriate content for each standard.
- Consulting widely across all relevant stakeholders for feedback and comments on the standards. Two national stakeholder meetings were held to review the new content and structure and further input was sought at the BHIVA national conference in November 2017. The BHIVA Audit and Standards Subcommittee participated in the design of the auditable outcome measures. A web consultation process was undertaken in January and February 2018, and the Standards were further amended in the light of feedback received.

According to the National Involvement Standards (2017), people living with HIV should have meaningful involvement in developing services, policies and decisions affecting them. To ensure the voices and opinions of people living with HIV were heard and acted upon during the development of these Standards, people living with HIV were involved throughout the process. People living with HIV attended and contributed to the stakeholder meetings and to the Steering Group. In addition, every Writing Group included at least one person living with HIV. By working together in this way, everyone involved was able to contribute to developing more effective and impactful services.

### Contributors

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Alan Winston	Imperial College London



## London Stakeholder Meeting

Monday 6th November 2017, University College London

### Attendance list

Allan Anderson	Positively UK
Yusef Azad	National AIDS Trust
Tristan Barber	BASHH
Garry Brough	UK-CAB
Fiona Burns	Co-chair
Sharon Byrne	HIVPA
Carlos Corredor	NAZ
Alastair Duncan	DHIVA
Jose Figueroa	Public Health England/NHS England (London Region)
Antonio Giacalone	Positive East
Jeffrey Grierson	Anglia Ruskin University
Jason Hale	UK-CAB
Rebecca Hall	Mawbey Group Practice
Lucy Hedley	HIVPA/Mortimer Market Centre/University College London Hospitals
Simon Horvat-Marcovic	UK-CAB
Alison Howarth	Coordinator
Alison Jenkin	St George's Hospital
Jo Josh	UK-CAB
Bernard Kelly	St George's Hospital
Christabel Kunda	NAZ
Chon Lam	St George's Hospital
Emily Mabonga	Lewisham and Greenwich NHS Trust
James Miller	Living Well CIC
Jayran Mistry	Blackfriars Medical Practice
Maureen Ndawana	African Health Policy Network
Kennedy Nkhoma	King's College London
Achyuta Nori	Guy's and St Thomas' NHS Foundation Trust
Christian Pankhurst	RHIVA/Guy's and St Thomas' NHS Foundation Trust
Mel Rattue	UK-CAB/Positively Mindful CIC
Iain Reeves	Homerton University Hospital
George Rodgers	H.A.D Support UK
Sophie Strachan	Sophia Forum
Ann Sullivan	Co-chair
Jaime Sylla	Positive East
Chris Taylor	King's College Hospital
Roy Trevelion	HIV i-Base
Ian Williams	CNWL/HIV CRG

## Manchester Stakeholder Meeting

Tuesday 7th November 2017, Friends' Meeting House, Manchester

### Attendance list

Alec Bonington	Pennine Acute Hospitals NHS Trust
David Chadwick	Co-chair
Kathleen Charters	Sahir House
Ben Cromarty	North Yorkshire AIDS Action/UK-CAB
Steven Duffy	HIV Scotland (patient rep)
Kathryn Gallon	North Yorkshire AIDS Action
Ellen Hill	Yorkshire MESMAC
Robert Houlgate	BHA Leeds Skyline
Alison Howarth	Coordinator
Kaveh Manavi	University Hospitals Birmingham NHS Foundation Trust
Sheila Morris	Co-chair
Adela Mugabo	George House Trust
Elizabeth Okecha	BASHH
Liz Porter	Terrence Higgins Trust
Sarah Schoeman	Leeds Teaching Hospitals NHS Trust
Alex Sparrowhawk	Terrence Higgins Trust
Adele Torkington	HIVPA/North Manchester General Hospital

## Community group involvement

### In Standards Steering Group and Writing Groups

HIV i-Base  
National AIDS Trust  
North Yorkshire AIDS Action  
Positively Mindful CIC  
Positively UK  
Sahir House  
Salamander Trust  
Sophia Forum  
The People Living with HIV Stigma Index UK  
UK-CAB  
Waverly Care

### London Stakeholder Meeting

African Health Policy Network  
H.A.D Support UK  
HIV i-Base



1

Living Well CIC  
National AIDS Trust

2

NAZ

3

Positive East

4

Positively UK

5

Sophia Forum

6

UK-CAB

7

Positively Mindful CIC

8

### Manchester Stakeholder Meeting

A

BHA Leeds Skyline

1

George House Trust

2

UK-CAB

3

North Yorkshire AIDS Action

4

Sahir House

5

Terrence Higgins Trust

6

Yorkshire MESMAC

### Responses to online public consultation

African Health Policy Network

Catholics for AIDS Prevention and Support

H.A.D Support UK

Leicestershire AIDS Support Services (LASS)

LGBT Foundation

National AIDS Trust

Positive Catholics

Positive East

Salamander Trust

Scottish Drugs Forum

Sophia Forum

Terrence Higgins Trust

UK-CAB

# Appendix 5

## NHS Outcomes Framework

The NHS Outcomes Framework is a set of indicators developed by the Department of Health to monitor the health outcomes of adults and children in England. The framework provides an overview of how the NHS is performing. The indicators relevant to HIV care are listed below, with the corresponding link to the BHIVA Standard(s).

### Domain 1: Preventing people from dying prematurely – overarching indicators

1a Potential years of life lost from causes considered amenable to healthcare – link to 1a, 1b, 3, 4 and 7d

### Domain 2: Enhancing quality of life for people with long-term conditions

2 Health-related quality of life for people with long-term conditions

Ensuring people feel supported to manage their condition

2.1 Proportion of people feeling supported to manage their condition – link to 2b and 2c

Reducing time spent in hospital by people with long-term conditions

2.3 i Unplanned hospitalisation for chronic ambulatory care sensitive conditions – link to 3b and 4a

Enhancing quality of life for carers

2.4 Health-related quality of life for carers (ASCOF 1D) – link to 2c and 4c

Enhancing quality of life for people with mental illness

2.5 i Employment of people with mental illness (ASCOF 1F and PHOF 1.8)

Enhancing quality of life for people with dementia – link to 6

Improving quality of life for people with multiple long-term conditions – link to 4b

2.7 Health-related quality of life for people with three or more long-term conditions (ASCOF 1A)

### Domain 3: Helping people to recover from episodes of ill health or following injury

3.1 Total health gain as assessed by patients for elective procedures

ii Psychological therapies – link to 5a

### Domain 4: Ensuring that people have a positive experience of care

4b Patient experience of hospital care – link to 3b and 4a

4c Friends and family test – link to 4a

Improving women and their families' experience of maternity services

4.5 Women's experience of maternity services – link to 5b

Improving experience of healthcare for people with mental illness

4.7 Patient experience of community mental health services – link to 6

### Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm

5a Deaths attributable to problems in healthcare – link to 1a and 7d

5b Severe harm attributable to problems in healthcare – link to 1a, 2b, 2c, 3a, 7c and 7d

Note: PHOF – Public Health Outcome Framework; ASCOF – Adult Social Care Outcome Framework



# Appendix 6

## Screening measure options for psychological assessment

### Anxiety screen - GAD-2

Over past 2 weeks, how often have you been bothered by:

Feeling nervous, anxious, or on edge

Not being able to stop or control worrying

0=Not at all/1=Several days/2=More than half the days/3=Nearly every day

- Kroenke K, Spitzer RL, Williams JB et al. (2007). Anxiety Disorders in Primary Care: Prevalence, Impairment, Comorbidity, and Detection. *Ann Intern Med* 2007; 146: 317-325.

### Depression screen - PHQ-2

Over past 2 weeks, how often have you been bothered by:

Little interest or pleasure in doing things

Feeling down, depressed, or hopeless

0=Not at all/1=Several days/2=More than half the days/3=Nearly every day

- Kroenke K, Spitzer RL, Williams JB. The Patient Health Questionnaire-2: validity of a two-item depression screener. *Med Care* 2003; 41: 1284-1292.

### PTSD screen

1. During your lifetime, as a child, or adult, have you experienced or witnessed traumatic event(s) that involved harm to yourself or others?
2. If 'yes' in the past year, have you been troubled by flashbacks, nightmares, or thoughts of the trauma?

### Alcohol and drug misuse screen

1. In the last year, have you ever drunk or used drugs more than you meant to?
2. Have you felt you wanted or needed to cut down on your drinking or drug use in the last year?

Where  $\geq 1$  positive may be suggestive of a problem

- Brown RL, Leonard T, Rounds LA, Papasouliotis O. A two-item screening test for alcohol and other drug problems. *J Fam Pract* 1997; 44: 151-160.
- Brown RL, Leonard T, Saunders LA, Papasouliotis O. A two-item conjoint screen for alcohol and other drug problems. *J Am Board Fam Pract* 2001; 14: 95-106



## Cognitive screening questions

1. Do you experience frequent memory loss? (e.g. you forget the occurrence of special events, even the more recent ones, appointments etc.)
2. Do you feel that you are slower when reasoning, planning activities or solving problems?
3. Do you have difficulties paying attention (e.g. to a conversation, a book or a movie?)
  - Simioni S, Cavassini M, Annoni JM et al. Cognitive dysfunction in HIV patients despite long-standing suppression of viremia. *AIDS* 2010; 24: 1243-1250.

## Cognitive screening measures - generalist

### Montreal Cognitive Assessment

- Nasreddine ZS, Phillips NA, Bédirian V et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc* 2005; 53: 695-699.

### Mini-mental state

- Folstein M, Folstein SE, McHugh PR. 'Mini-mental state' a practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975; 12: 189-198.

### Addenbrooke's Cognitive Examination (third edition)

- Hsieh S, Schubert S, Hoon C et al. Validation of the Addenbrooke's Cognitive Examination III in frontotemporal dementia and Alzheimer's disease. *Dement Geriatr Cogn Disord* 2013; 36: 242-250.

## Cognitive screening measures - computer based

### Cogstate

- Maruff P, Thomas E, Cysique L et al. Validity of the CogState brief battery: relationship to standardized tests and sensitivity to cognitive impairment in mild traumatic brain injury, schizophrenia, and AIDS dementia complex. *Arch Clin Neuropsychol* 2009; 24: 165-178.

### CANTAB

- Sahakian BJ, Elliott R, Low N et al. Neuropsychological deficits in tests of executive function in asymptomatic and symptomatic HIV-1 seropositive men. *Psychol Med* 1995; 25: 1233-1246.

## Cognitive screening measures - HIV related

### HIV Dementia Scale

- Power C, Selnes OA, Grim JA, McArthur JC. HIV Dementia Scale: a rapid screening test. *J Acquir Immune Defic Syndr Hum Retrovirol* 1995; 8: 273-278.

### International HIV Dementia Scale

- Sacktor NC, Wong M, Nakasujja N et al. The International HIV Dementia Scale: a new rapid screening test for HIV dementia. *AIDS* 2005; 19: 1367-1374.



