

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 which cover 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 which 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 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 co-morbidities of an aging 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. PrEP) has resulted in improvements in both 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. This continues to be important since the introduction of the new NHS commissioning landscape in April 2013. 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. 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 (HIV 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 ARVs are prescribed and monitored safely (anti-retroviral prescribing) wherever they live.

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

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 covers 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 life. 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 health care 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. It is 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.

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Consultation draft

Introduction and background

Introduction

HIV continues to be a significant clinical and public health issue in the UK, since it's identification as the causative agent of Acquired Immune Deficiency Syndrome (AIDS) in 1983. Despite huge advances in antiretroviral therapy and consequent improvement in clinical outcomes, HIV remains a stigmatised and under-recognised condition that disproportionately affects already vulnerable populations. The biomedical, social, ethical and structural challenges associated with HIV all impact on the provision of best 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

It is estimated that 101,200 people were living with HIV in the UK in 2015, of whom an estimated 13% were unaware that they were HIV positive (PHE 2016). The majority (96%) of those attending HIV clinics were on antiretroviral therapy (ART) and of these 94% had an undetectable viral load. In 2015, 6,095 people were newly diagnosed with HIV. Challenges remain with 39% of HIV diagnoses made at a late stage of infection in 2015. Late diagnoses 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, one in three people living with diagnosed HIV in the UK were aged 50 years or over. 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 2,580 births to women diagnosed with HIV in 2012-2014, continuing the decline from 0.46% in 2010-2011 and 2.1% in 2000-2001 (Peters et al, 2016).

Despite these advances, late presentation of HIV continues to carry significant risks of morbidity and mortality, reduced life expectancy, and increased rates of hospitalisation. In 2016, 42% of people newly diagnosed with HIV presented at a late stage of infection with a CD4 count below 350 cells/mm³. Despite the move to a policy of early treatment for all, this definition is likely to remain pertinent, given its clinical correlation to risk of serious harm. Undiagnosed, untreated and the more-advanced stages of HIV infection facilitate onward transmission, compromising both individual well-being and the wider public health. Health care 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 were over 50 years old. 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 a growing number of new HIV infections, increased life expectancy for people living with HIV, greater use of antiretroviral drugs and health care services, and changing co-morbidities 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. 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, which are specific, concise statements about the care that any adult living with HIV in the UK should expect to receive. 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, this means that 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 of infection, 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 infection, 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 highlight the range of prevention options, 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.

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 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 health care
- Service providers throughout the UK who are involved in any aspect of the delivery of health care 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.

Development of the standards (for additional details see Appendix 2)

Input from a wide range of stakeholders has been sought to ensure that the Standards incorporate the key aspects of health care 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 and will facilitate delivery of the NHS Outcome Frameworks 2017/2018.

The development of these standards has included review and update of the 2013 Standards of Care; re-drafting of standards and drafting of 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 care for HIV infection. 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.

The NHS Outcomes Frameworks 2017/2018 and the NHS Quality, Innovation, Productivity and Prevention (QIPP) programme

Throughout the process these standards have 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 QIPP agenda while sustaining high-quality care (see Appendix 3).

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 health care for people living with HIV

Service provision needs to evolve to effectively and efficiently to meet the changing needs of people living with HIV. This means that 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 the best health outcomes for people living with HIV.

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 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.

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 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, physical ability, health literacy, immigration or residency status. HIV remains a stigmatised and socially complex diagnosis which disproportionately affects already marginalised population groups. People living with HIV should be provided equitable and non-discriminatory care across all health and social care settings
3. All patient related information whether clinical, pseudonymised 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 health care 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, the Joint United Nations Programme on HIV/AIDS (UNAIDS) launched the 90:90:90 ambition which set out a global target, 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. Late diagnosis of HIV (CD4 count <350 cells/mm³ at the time of diagnosis) is associated with increased short- and long-term morbidity and mortality. Survival following HIV-associated opportunistic disease is associated with avoidable, potentially lifelong, morbidity. Unfortunately, timely diagnosis is an ongoing challenge in the UK. In 2015, 39% of people who were newly diagnosed HIV positive were diagnosed late.

Prompt HIV diagnosis also affords opportunities to reduce transmission of HIV to other people. Recognising primary HIV infection (recent HIV infection/ seroconversion illness) is important. This is a stage of high viraemia and hence infectiousness. Assays used should be appropriate to capture all stages of HIV infection.

UK data from a wide range of clinical and community based interventions has 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 tailored to local populations and maximise the opportunity for testing in both clinical and non-clinical settings. Community testing initiatives have been found particularly effective among men who have sex with men (MSM) and black African populations.

Self-sampling and self-testing methods have emerged as an acceptable and convenient method for accessing a HIV test. There is an increasing number of providers of such testing kits which require 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-testing.

Materials and interventions for promoting awareness and increasing the uptake of HIV testing should have clear messaging and be designed in line with NICE's recommendations on behaviour change and patient experience. There are significant personal and social consequences of an HIV positive diagnosis which should be recognised in any setting where HIV testing is being carried out. Arrangements should be in place for appropriate onward treatment, care and support as required, including access to peer support.

Quality statements

- We recommend that a routine offer of HIV testing should be made by competent health care professionals to all attendees in all the following settings and clinical scenarios:
 - Contraceptive and sexual health services
 - Termination-of-pregnancy services
 - Drug-dependency programmes
 - Antenatal services
 - Services for TB, lymphoma and hepatitis B and C
 - All people with symptoms that are consistent with primary HIV infection
 - All people presenting with a clinical indicator condition specified in the UK National HIV testing guidelines
 - All people at first reception into prison services
- People presenting to clinical services where HIV may be an explanation for their condition should be recommended to have an HIV test.
- All those who present to medical services with identifiable risk factors (behavioural and geographical) should be offered an HIV test in accordance with national guidance.
- In areas where the prevalence of diagnosed HIV infection is 2:1000 or greater, all men and women admitted for secondary general medical care, including Emergency Departments, Medical Assessment Units, Intensive Care Units and mental health services should have routine, opt-out HIV testing included in their initial health checks and medical work-up. Sustainability of opt testing in wider medical settings will require local and or national policy such as CQUINs to incentivise all relevant stakeholders to embed HIV testing into their clinical pathways.
- In areas where the prevalence of diagnosed HIV infection is 2:1000 or greater, all men and women registering with a general practice 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 infection is 2:1000 or greater, all men and women having a blood test at their general practice should be offered a HIV test if they have not had a HIV test 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 carefully recorded in the patient's medical record. Reasons for declining a test should be explored. Written information about HIV testing can be given to the patient and testing should be re-offered at the next earliest opportunity. In addition, the availability and use of community testing should be encouraged and advertised, with appropriate funding from local authorities.

- 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 (for example, following a needlestick injury);
 - In situations where it would be difficult to give people their results, for example if they are unwilling to leave contact details;
 - If a person refuses to give a venous blood sample.
- We recommend that at the time of their point-of-care test (POCT), people should be informed of the specificity and sensitivity of the POCT being used and that confirmatory serological testing will be needed if the test is reactive.
- When primary HIV infection (PHI) is a potential diagnosis, we recommend the use of diagnostic HIV assays which can simultaneously identify both antibodies to HIV and HIV p24 antigen (fourth-generation assays).
- 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.
- We recommend annual testing to people in groups or communities with a high rate of HIV, and more frequently if they are at ongoing high risk of exposure. For example: men who have sex with men should have HIV and other sexually transmitted infection tests at least annually, and every 3 months if they are having condomless anal sex with new or casual partners.
- We recommend that 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 individuals diagnosed late (CD4 count <350 cells/mm³) or very late (CD4 count <200 cells/mm³ or AIDS). A transient or early low CD4 count is not uncommon in PHI. Therefore, considering CD4 count alone may overestimate the proportion of individuals diagnosed late. Audits of late diagnosis should ideally take into account the clinical stage at diagnosis. Those with recent infection presenting with a transient or early low CD4 count should be excluded.
- All HIV services should undertake a review of all patients diagnosed late (CD4 count <350 cells/mm³) or very late (CD4 count <200 cells/mm³ or AIDS), with 'look back' of previous engagement with health care services. This critical case review should be line with the forthcoming national standardised process for reviewing late diagnoses which is currently in development.
- A mechanism should be established to routinely provide constructive feedback to clinical areas considered to have missed important earlier diagnostic opportunities.
- A summary of the late diagnosis review should be provided to commissioners to aid greater understanding for interventions which can be implemented to reduce late diagnosis annually.

- The proportion of people newly attending at sexual health services with a documented offer of an HIV test in their clinical record (target: 98%).
- In areas where the prevalence of diagnosed HIV infection is 2:1000 or greater, the proportion of new adult registrants in general practice with a documented offer of an HIV test, either at new patient check or first clinical consultation, in their clinical record (target: 98%).
- In areas where the prevalence of diagnosed HIV infection is 2:1000 or greater, the proportion of new registrants in general practice with a documented offer of an HIV test, either at new patient check or first clinical consultation, who also have a documented HIV test result in their clinical record (target: 98%).
- In areas where the prevalence of diagnosed HIV infection is 2:1000 or greater, the proportion of those admitted to secondary care with a documented offer of an HIV test during their admission (target: 98%).
- In areas where the prevalence of diagnosed HIV infection is 2:1000 or greater, the proportion of those admitted to secondary care with a documented offer of an HIV test during their admission who have a documented HIV test result in their clinical record (target: 98%).
- Proportion of services using the required HIV assays with a process for quality control.
- Time between undertaking HIV testing and results being available and/or shared with the patient.

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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 anti-retrovirals (ARVs) as post-exposure prophylaxis, 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. There is no single, “one size fits all” solution when it comes to HIV prevention. HIV prevention requires complex behaviour change which is influenced by many factors. 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 a focus on only primary prevention for HIV negative people, and also work with people living with HIV as important partners in prevention.

The HIV prevention landscape is changing dramatically and there is an ever-increasing array of evidence-based, HIV prevention tools available. These include condoms, STI screening and treatment, partner notification, motivational interviewing, anti-retrovirals (ARVs) to prevent mother-to-child transmission and as post-exposure prophylaxis, and vaginal microbicides. Particularly notable in recent years is the use of ARVs by HIV-negative and -positive individuals to reduce HIV acquisition and transmission in the form of pre-exposure prophylaxis (PrEP) and treatment as prevention (TasP), respectively. It is clear that people living with HIV, with a sustained, undetectable viral load in their blood cannot transmit HIV to their sexual partners. All patients should be made aware of this, which is itself a powerful tool in HIV prevention.

PrEP consisting of oral tenofovir-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 men who have sex with men (MSM) having condomless anal sex, and revealed a sub-group of MSM who are at imminent risk of HIV and who need additional risk reduction support over and above standard prevention care. Other groups have collected similar strong evidence for the benefits of PrEP in heterosexuals 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 risk reduction support.

NHS access to PrEP is variable across the UK, with widespread accessibility only in Scotland and Wales. Individuals in England have two options for accessing PrEP: either by purchasing PrEP from pharmacies outside the European Union selling generic products 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 GUM clinics). The Public Health Agency for Northern Ireland are reviewing PrEP provision and a report is expected soon. In the interim PrEP monitoring is being provided in sexual health clinics.

Despite limited access, the game-changing potential of PrEP has been borne out in at least five London sexual health clinics which have seen the number of new HIV diagnoses reduce dramatically over 2 years. This is thought to be primarily due to increased testing of the most high-risk individuals, earlier ARV treatment initiation (to effect treatment as prevention: TasP) and the increasing use of PrEP privately and via research studies.

Transmission risk is a major concern for people living with HIV and their sexual partners. The knowledge of the impact of successful treatment on transmission risk is a powerful tool to support people living with HIV and a challenge to the stigma that they often face. Data from studies such as PARTNER and Opposites Attract provides overwhelming evidence that in both heterosexual and male same sex sero-discordant couples the chance of a person living with HIV who has an undetectable viral load transmitting their virus is negligible; all people living with HIV should be provided with this information and its implications. TasP is another cost-effective approach and we advocate that HIV clinicians discuss and offer TasP with all newly diagnosed patients whatever their CD4 count.

We know there are 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 with available prevention tools.

Quality statements

- An assessment of the risk of transmission to others should be made at diagnosis and subsequent visits.
- We recommend that people living with HIV should be made aware of the range of interventions which have been shown to reduce risk of onward HIV transmission, including the risks and benefits.
- People living with HIV who are assessed as being at risk of transmission to others should be offered one-to-one risk reduction based on a theory of behaviour change (See Standard 5a).
- All HIV services should promote condom use as a safer sex strategy.
- All HIV services should ensure that a range of condoms (male, female, various sizes and types) and lubricant are provided and available for people living with HIV.
- All HIV services should raise awareness of the role of STIs in the context of HIV acquisition and transmission.
- We recommend that people living with HIV should be made aware of the evidence that treatment with ARVs substantially lowers the risk of transmission and once viral load is sustained at undetectable, there is effectively no risk of sexually transmitting the virus to an HIV-negative partner.
- HIV services should be able to demonstrate that they have care pathways for partners of people living with HIV to access PrEP as appropriate.
- We recommend that PrEP should be considered in all HIV negative people on a case-by-case basis.

- We recommend that PrEP with regular or event-based oral tenofovir with emtricitabine (TDF-FTC) is offered to
 - Men who have sex with men and transgender women at elevated risk of HIV acquisition through recent (3–6 months) and ongoing condomless anal sex.
 - HIV-negative people having condomless sex with partners who are living with HIV, unless the partner has been on antiretroviral treatment (ART) for at least 6 months and their plasma viral load is <200 copies/mL.
 - Others considered to be at high risk.
- We recommend that PrEP should be delivered as part of a comprehensive package of HIV/STI prevention services, 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.
- We recommend that partners of people who test HIV positive should receive a prompt offer and recommendation of an HIV test through partner notification procedures (See Standard 1a).
- We recommend that partners of people who test HIV positive should receive a prompt offer of post-exposure prophylaxis (PEP), if recently exposed, through partner notification procedures (See Standard 1a).

Measurable and auditable outcomes

- Documented evidence that people living with HIV have had a discussion about HIV transmission and HIV prevention options, including advice that ARVs substantially lower the risk of transmission (target: 98%).
- Documented evidence that people living with HIV who may be at risk of passing on HIV to others have been offered one-to-one risk reduction based on a theory of behaviour change (See Standard 5a) (target: 98%).
- Documented evidence that people living with HIV with sustained viral suppression (at least 6 months) and high adherence to ART have been advised that there is effectively no risk of sexually transmitting the virus to an HIV-negative partner (target: 98%).
- Evidence of a patient experience survey to assess satisfaction regarding discussion around HIV transmission and HIV prevention options.

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2. Person-centred care

Good quality care should focus on the person and not only their illness [1, 2]. The BHIVA Standards aim to ensure that care for people living with HIV is “person-centred”. Person-centred means that it consciously adopts the perspectives of individuals, families and communities and sees them as participants not just beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways [3]. Person-centredness “considers people’s desires, values, family situations, social circumstances, and lifestyles; seeing the person as an individual” [4].

When people living with HIV are with health care professionals, it is important they are asked about their problems, symptoms and concerns. However, evidence suggests that they are not routinely asked about these issues [5]. Psychological and social problems persist alongside antiretroviral treatment (ART), as does the experience of stigma [6]. People living with HIV in the UK can report a high burden of pain, other symptoms and psychological concerns [7], and these are associated with other challenges such as poorer adherence, suicidal ideation, poorer quality of life, and treatment switching [8-11]. 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 [12].

2a. Stigma - equitable and non-discriminatory care

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

Rationale

Stigma was originally conceptualised from an individual perspective by Goffman (1963) 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.

The Equality Act applies in England and serves as protection against discrimination, including professional and healthcare 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.

A relationship has also been shown between experiences of HIV-related stigma and self-efficacy and health-related behaviours. There is good evidence that stigma is also associated with reduced engagement with healthcare services. One in eight participants of the Stigma Survey UK had avoided seeking care in the previous 12 months.

Quality statements

- Staff at all healthcare services, including general practitioners and dentists, should receive basic information and training on blood borne viruses and access to resources to supplement their existing knowledge on treating people with HIV.
- All healthcare services should ensure that staff are aware of the confidential nature of people's medical records, including their HIV status
- Patients should be made aware of how they can raise concerns if they are unhappy with their care and should be supported in doing so. Patients should be reassured this will not affect access to or standard of their care.

Measurable and auditable outcomes

- Recruitment of 10% of patients to complete the NHS national patient experiences survey to assess satisfaction with their care
- Evidence of all staff receiving education and training on equality and discrimination. Staff should also receive specific training on HIV related stigma and the potential impact this has on people's health and well being.
- Evidence of a named lead for stigma
- Evidence that departments provide information to staff in the form of posters or leaflets

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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 by people with the condition. As with many other long-term conditions, self-management approaches can help people with HIV gain confidence, skills and knowledge to manage their own health, with resulting improvements in health, quality of life and independence.

It is important to recognise that the resources required to effectively self-manage will change across the life course and with changes in physical health- both HIV and non-HIV related. Self-management issues around key life phases and moments, for example entry and re-entry into the workforce, establishing relationships, sexual debut, coping with loss, ageing, retirement, transitioning from paediatric to adult services, will require different strategies and resources and have implications for different services.

UK health policy encourages an increased focus on self-management. Evidence shows that limited health literacy contributes to sub-optimal care, poorer health status of affected individuals 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 involves people 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 not only ways to manage current challenges but preparedness for future challenges. It is in this area that strong networks of peer support can be particularly beneficial.

HIV-associated stigma has many negative effects on the lives of people with HIV, undermining confidence and acting as a barrier to service uptake and utilisation. People with HIV will differ in their experience of stigma, historically, geographically and in relation to social context. Appropriate peer support enables people 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.

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

- Physical health, including HIV-specific issues, co-morbidities 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 prevention of mental illness and resilience building

- Economic inclusion and well-being, including access to financial and employment support
- Social inclusion and well-being, including peer support

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

- People 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.

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 with HIV to contribute to communities.

Services that provide care for people with HIV should be delivered in a way that not only supports but also facilitates self-management, and encourages staff to operate a strong self-management philosophy. This should include an assessment of the individual self-management needs, followed by assistance to access resources (including peer support, interventions and online resources) to develop confidence and competencies for living with HIV. Useful approaches include the use of information, techniques and tools together with the provision of skills development through interventions such as coaching. Working with people with HIV to identify their self-management needs, staff should be able to offer referral to services, professionals and peer-support groups that will most effectively enhance their ability to self-manage. Occupational therapists, physiotherapists and speech and language therapists can collaboratively work with people living with HIV to identify goals, engage in a rehabilitation programme to achieve them, optimise function and develop self-management techniques. Referral to dietitians can facilitate or support lifestyle behaviour changes that will either prevent or reduce the risk of long-term consequences associated with poor nutrition.

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. HIV services should develop delivery models using information technology that supports people in achieving the goal of greater self-management. 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, irrespective of race, age, gender, disability or where they live.

Quality statements

People living with HIV should have equitable access to services which promote self-management of HIV including:

- Provision of practical and empowering support and information about HIV, treatment, healthy living with HIV, diet and lifestyle, and optimisation of general health including rehabilitation services.
- Provision of support and information on maximisation of entitlement to health services and support.
- Provision of support, information and resources 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 , this includes:
 - A range of interventions in place to meet the needs of people living with HIV such as: face-to-face, online, group support, workshops; Services tailored to specific communities e.g. gay and bisexual men, women, African communities
 - Referral arrangements in place to enable people living with HIV to access HIV support services
 - Services delivered by providers with appropriate expertise and competencies. Wherever appropriate and relevant, providers should have the requisite professional qualifications and be appropriately accredited.
 - Increasing the involvement of skilled peer workers with HIV in service delivery, thus optimising integral peer-to-peer self-management support. These skilled peer workers should have a structured recruitment and training process and have access to appropriate supervision and professional development
- HIV services should maximise opportunities for patients to self-manage their condition.

Measurable and auditable outcomes

- Proportion of people feeling supported to manage HIV (NHS England Outcome 2.1). (Target 90%)
- Agree pathway from the clinic to peer support and self-management which can be tiered depending upon resources (Target 90%)
 - Signposting and information given to patients
 - Referral pathways and sharing of data in place between the clinic and agency providing peer support
 - Peer support integrated and delivered within the clinical setting

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2c. Participation of people with HIV in their care

People living with HIV should be actively involved in decisions about their own health and social care. Ensuring active engagement in decision making may require support and resources for both people living with HIV and service providers.

People who use HIV clinical and support services should be actively involved in the design, planning, delivery and review of these services. This may require support, training and resources for individuals and groups engaged in this process.

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

Individual decisions about 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 which apply to all decisions about care. Other professional regulatory bodies and national NHS guidance (for example NICE) set out similar requirements. In summary these set out 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

HIV is a life-long manageable condition. Antiretroviral treatment (ART), once started, is generally continuous and ongoing. Successful responses to therapy depend on achieving optimal adherence with minimal adverse effects. A focus on quality of life by using effective drugs with minimal toxicity is essential if people with HIV are to lead active, productive and fulfilling lives. Undetectability also means that people with HIV do not pass on the virus to others.

British HIV Association guidelines recommend that people with HIV be given opportunities to be involved in making decisions about their treatment including ART. Trust and good communication between the person receiving care and the health care practitioner lead to better adherence and outcomes. A range of information resources and support services are available to help including promoting treatment literacy. 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, for example, depression, memory problems or 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, for example 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 with HIV in their health care supports long-term, chronic condition self-management (see Standard 2b). Shared decision-making and self-management can be supported by high-quality, accessible information and support services together with appropriate decision-making tools. The experiences of people receiving health care are important measures of service quality.

Planning services

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

People with HIV have consistently advocated for participation in decision-making about services they use and for people 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 health care is enshrined in law and clarified in NHS guidance.

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 medical care for HIV is provided within the NHS, GUM 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 long term medical management of HIV will need greater involvement from care closer to home using Primary care/GP services as is the case with other long-term conditions such as diabetes, COPD, 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 with HIV and practitioners follow national guidance and professional standards for shared decision-making in all aspects of care.
- Services should ensure that decisions about ART follow British HIV Association guidelines for patient involvement in decision-making.
- Services should ensure that people 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 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 co-morbidities and other long-term conditions
 - Information about improving general health outcomes
- 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.
- People 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, of the person receiving care.

- Making shared decisions about health care requires specific skills and confidence. Access to decision-making tools may help discussion on particular aspects of care.
- Developing capability for shared decision-making should be encouraged and facilitated in clinicians, people 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.

Planning services

To ensure that services are fit for purpose and responsive to users' needs, opportunities (formal and informal) should be available for people 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.

Service users 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. Service user involvement should be incorporated into national treatment 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 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

Individual decisions about treatment and care

- Proportion of people who are satisfied with decisions about their care (target: 90% of total people).
- Proportions of people who receive written information about their ART, including details for each drug prescribed, or confirm they 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% of total people).
- The BHIVA patient-reported outcome measure should be used to identify symptoms concerns, priorities and outcomes of care in 90% of those with sufficient capacity to participate

Planning services

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

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2d. Well-being

People with HIV should receive care that takes account of and enhances their well-being beyond their physical health and life expectancy.

The World Health Organization (WHO) defined health in its broader sense in its 1948 constitution as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity". While well-being is an integral part of health within most accepted definitions, it is often overshadowed by the more tangible and concrete aspects of physical health. 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.

Including a specific standard of care 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.

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. There is a recognition that 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 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 inclusion of 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 which 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.

Importantly, while there are clear intersections between considerations of 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.

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
- Feedback and input is 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

Measurable and auditable outcomes

Optimal well-being is achieved through a combination of factors, of which HIV care is but one. 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, stigma and social exclusion within the remit of the service will assist in optimising life outcomes for people living with HIV. The outcomes listed below include those that are most likely to be directly addressed within HIV care services and those which assist in understanding the broader well-being context of the PLIV population.

Within HIV Care

- The proportion of people with a care coordinator (Target 75% of appropriate people)
- The proportion of people who have an assessment for and access to mental health support services (Target 75% of appropriate people)
- The proportion of people have an assessment for and access to drug and alcohol misuse support (Target 75% of appropriate people)

- The proportion of people have an assessment for and access to support for intimate partner violence (Target 75% of appropriate people)
- The proportion of people have an assessment for and access to support around accessing benefits and financial hardship (Target 75% of appropriate people)
- Evidence of an agreed pathway from the clinic to peer support and self-management (see Standard 2b - self-management and peer support)
- Evidence of participation in integrated care planning and communication between agencies (HIV clinics, other areas of health care, GPs, specialist services, support services, social care services)
- Evidence of the use of HIV PROMs/PREMs to assess patient experience (Target 95% of all people)

Beyond HIV Care

- The proportion of people who report good quality of life
- The proportion of people who report accessing wider healthcare services without experiencing stigma and discrimination
- The proportion of people who report being able to access mental health support in a timely manner
- The proportion of people who have the financial and social resources to meet basic needs
- The proportion of people who have the financial and social resources to meet physical and social needs consistent with a reasonable quality of life (for example access to entertainment, opportunities to socialise, travel etc.)
- The proportion of people who report that their care is planned around them, co-ordinated and integrated

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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 for those who miss appointments or who transfer their care to another centre, to ensure people 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 antiretroviral therapy treatment, and, ultimately, suppression of the virus. In practice, an individual does not simply, sequentially move through each stage of this continuum. Engagement in care is dynamic and disengagement from care may happen at any time.

The prognosis for people with HIV infection who engage fully with specialist HIV care with high-quality, tailored multidisciplinary management continues to improve, with ongoing reduction in morbidity and mortality. Those who are diagnosed promptly and treated successfully with antiretroviral therapy (ART) now have a similar life expectancy to that of the general population.

For optimum outcomes people with newly diagnosed HIV infection require rapid access to HIV specialist 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 who is newly diagnosed with HIV should be seen for this specialist assessment within two weeks of receiving an HIV positive diagnosis. People newly diagnosed with HIV who have symptoms and/or signs attributable to HIV infection (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. Rapid 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 for people as they adjust to their diagnosis (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 their needs, with an initial appointment as soon as possible after treatment.

The 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 with HIV through the process. This requires access to practitioners with skills in partner notification without delay following a diagnosis of HIV (see Standard 5a).

HIV remains a stigmatised and socially complex diagnosis which disproportionately affects already marginalised population groups. This may further complicate the situation when someone is first made aware of their infection. People 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 with HIV feel secure and where their confidentiality and autonomy is actively respected.

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 for 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 continuum for a variety of reasons. These reasons may result from both patient- and service-related 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 highlights 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 enough 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. Close working links between health, social care, legal services, benefit agencies, peer support and voluntary sector agencies is required in these situations to maximise well-being.

People 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 infected children living 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

- All 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 fully assessed by appropriately trained staff within 2 weeks of receiving an HIV positive test result.
- People who have a new diagnosis of HIV and have symptoms and/or signs potentially attributable to HIV infection (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 infection.
- People who have a new diagnosis of HIV should expect to have access to appropriately trained HIV specialist professionals for opportunities to discuss emotional, psychosocial and partner notification issues relating to their HIV diagnosis as well as access to community support.
- People who have a new diagnosis of HIV should receive/have access to psychological support/information within 2 weeks of diagnosis.
- HIV outpatient units should have a policy/pathway to support access to peer support within 2 weeks of diagnosis.
- HIV outpatient units should have a policy/pathway for support and onward referral for those individuals who present in a situation of social and/or financial crisis.
- Adolescents moving from paediatric into adult care should expect their transition to be managed sensitively in accordance with separate guidance developed by CHIVA and BHIVA.
- People who have a new diagnosis of HIV should have the initial investigations/evaluations as recommended within the BHIVA guidelines for investigation and monitoring within 2 weeks of receiving their HIV positive result.
- People who have a new diagnosis of HIV should be informed of their CD4 count and have the opportunity to discuss management, starting antiretroviral therapy and opportunistic infection prophylaxis within 2 weeks of this initial assessment (i.e. within 1 month of initial diagnosis).

Retention

- All HIV services should have mechanisms to identify people with HIV, registered with their service, who become disengaged from care.

- Clinical HIV services should have mechanisms in place to follow up people with HIV who miss appointments, monitoring tests or run low on supplies of medication.
- Clinical HIV services should have mechanisms in place to explore the reasons of disengagement when people living with HIV re-engage with services after missing appointments.
- Services should aim to support retention in care and where possible address identified reasons for disengagement.
- People living with HIV should expect to have access to peer support whenever required, particularly when facing a significant life event such as starting/changing treatment, major illness, diagnosis of co-morbidity, pregnancy and menopause.
- People living with HIV should receive/have access to ongoing psychological support/information as needed to enable holistic well-being.
- All HIV services should have mechanisms in place to provide advice and support to improve lifestyle choices.
- If a patient is unhappy with the care provided by an individual clinician, an alternative should be offered (including referral to another centre if necessary) after exploration of the basis for concerns and addressing as appropriate.
- HIV services should have defined pathways 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 requested. This summary should contain as a minimum the information outlined in the BHIVA investigation and monitoring guidelines.

Measurable and auditable outcomes

- The 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%).
- The proportion of people newly diagnosed in primary care who are seen in an HIV specialist department within 2 weeks of diagnosis (target: >95%).
- The proportion of people newly diagnosed in secondary care who are seen in an HIV specialist department within 2 weeks of diagnosis/discharge from hospital (target: >95%).
- The proportion of people newly diagnosed in community settings who are seen in an HIV specialist department within 2 weeks of diagnosis (target: >95%).
- The proportion of people newly diagnosed with HIV who are offered referral for peer support in any form (target: >95%).
- The proportion of people with known HIV infection who are not known to have transferred their care or died, who have accessed HIV clinical services within the past 12 months (target: >95%).
- Patients attending HIV services 1 year ago who have not been lost to follow up – new diagnoses (numerator: number of patients in care at the beginning of the year who

have not died who were NEWLY diagnosed between 24 and 12 months ago and have received some aspect of care in the past 12 months; denominator: number of patients who were NEWLY diagnosed between 24 and 12 months ago).

- Patients attending HIV services 1 year ago who have not been lost to follow up – all patients (numerator: number of patients receiving some aspect of care in the past 12 months who have not died and who received some aspect of care between 24 and 12 months ago; denominator: number of patients who received some aspect of care between 24 and 12 months ago).
- Where peer support needs have been identified, excluding those newly diagnosed, the proportion of patients who report awareness of peer support services, and the proportion who report subsequent use of peer support (target: >95%).

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3b. Outpatient care

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

Rationale

Outpatient care for people with HIV should follow current national guidelines for support, monitoring and treatment to maximise the benefits of anti-retroviral therapy, to allow early detection of treatment- and HIV-related complications and to promote a good quality of life. Services should be person-centred: people with HIV who are less well engaged in care have a significantly increased risk of mortality.

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 the medical management through to the patient's experience of stigma and difficulties in communication with partners and family. The interfaces between HIV care and these other areas are particularly important and should be as smooth and seamless as possible.

People living with HIV who have more 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.

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 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.

All HIV services should have access to the full range of essential investigations routinely used in the management of HIV, including CD4 lymphocyte count, HIV viral load, HIV genotypic resistance testing, and should expect to receive results within 2 weeks of specimen collection.

Access to important aspects of healthcare is best achieved through primary care, particularly as patients age and become more likely to develop long term chronic illnesses. 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.

Quality Statements

- People with HIV attending specialist HIV outpatient services should receive care and treatment that follows national guidelines for the treatment of HIV infection and the complications of HIV infection and its therapy.
- People with HIV should receive care in appropriate designated facilities which guarantee privacy and confidentiality. There should be easy access to multidisciplinary support services – in particular: phlebotomy, specialist adherence support, specialist HIV pharmacy advice, dispensing services, 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 all other people living with HIV. Services should seek to provide flexible care arrangements for particularly vulnerable people e.g. homeless people.
- People with HIV should have access to appropriate sexual and reproductive health services offering sexually transmitted infection (STI) screening, treatment and advice as well as a full range of contraceptive choices, taking into account drug-drug interactions (see Standard 5).
- All services should have access to essential diagnostic investigations for the routine management of HIV and the complications of HIV therapy, as per national guidelines.
- All persons living with HIV should have access to peer and psychosocial support and advice according to national standards. There should be care 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 (see Standard 6).
- People with HIV should have access to services to safely manage comorbidities, in collaboration with the appropriate non-HIV specialist team and/or primary care. 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 pathways should exist for entry into more specialist services where people have less common or more complex problems.
- People living with HIV should have ready access to health promotion and screening services as for the general population.
- All 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.

- Where antiretroviral treatment choice is affected by resistance, drug interactions or comorbidities, this should be recognised and discussed at the appropriately specialist level, including representation from the relevant professional disciplines as specified in national guidelines. These arrangements may be physical or virtual.
- All HIV services should have a pathway in place so that patients have 24/7 access to emergency treatment and advice.
- All persons involved in providing care and support for people with HIV, including peer support, should receive the appropriate training and have the relevant specialist knowledge, skills and competencies in accordance with their relevant professional bodies

Measurable and auditable outcomes

Preventing premature mortality, reducing morbidity and preventing transmission

- Evidence that newly diagnosed patients are clinically assessed and offered the opportunity to start anti-retroviral treatment according to BHIVA guidelines (95%).
- Evidence that all patients have been given information, whether oral or written, about the effect of anti-retroviral therapy on the risk of transmission (95%).
- Evidence to demonstrate that all patients who experience viral rebound who were previously suppressed or where viral suppression is not achieved are managed according to national guidelines (95%).
- Important modifiable risk factors for longer term health such as smoking history, BMI and blood pressure should be recorded and documented according to BHIVA guidelines with formal cardiovascular risk calculation as specified by those guidelines.
- Proportion of patients with viral hepatitis screening and offer of appropriate vaccination as well as appropriate screening and advice about other vaccine preventable diseases (targets as specified in BHIVA monitoring and immunisation guidelines).
- Patients with a documented assessment of renal function, to include an assessment of proteinuria in the last 15 months (>90%).
- Evidence of achievement of national clinical quality outcomes.

Clinical practice in line with national guidelines

- Evidence that patients are monitored in accordance with BHIVA guidelines, whether on or off treatment.
- Evidence that genotypic resistance testing is performed according to BHIVA monitoring and treatment guidelines.

- Evidence that when patients transfer into the service an attempt is made to obtain the following information from the previous care provider: baseline resistance status, previous treatment regimens and the reasons for any treatment switch. This information should be recorded in the care record.
- HIV services should be able to demonstrate that they are able to provide results for HIV viral load, CD4 count, HIV resistance assay, HLA-B5701, and tropism tests within 2 weeks (target: 90%) of specimen collection

Patient experience

- Evidence of a designated and appropriate waiting area, consulting rooms and treatment rooms, with a layout and design that ensures patient confidentiality and privacy.
- Evidence of easy access to multidisciplinary support services – in particular: phlebotomy, specialist nursing, adherence, specialist HIV pharmacy advice, and peer and advocacy support.
- Evidence of ready access to defined care and support services, e.g. dispensing, mental health care, social care advice, sexual health advisor.
- Survey of patient experience in the preceding 3 years (target: 95%).

Patient safety

- Evidence of recording of clinical incidents and complaints and their investigation (target: 95%).
- Evidence of a care pathway whereby patients with viraemia and limited options to construct a fully suppressive regimen have their case reviewed directly or remotely (by virtual clinic) by a multidisciplinary team consisting of at least one consultant virologist, two HIV consultants, and a specialist HIV nurse or pharmacist. Evidence should be available to demonstrate that patients are reviewed via this clinic.
- Evidence of care pathways with a designated HIV inpatient service.
- Evidence of protocols/formalised pathways for integrated care or for referral of patients with complex HIV or conditions requiring specialist input, such as hepatitis coinfection, TB, or treatment-related end-organ damage.
- Evidence of participation in local and/or regional mortality review meetings with documentation of outputs for improvement.
- For stable patients: at least annual communication with GPs for those patients who have consented to share information with their GP, that patients have been offered a copy of this letter and that this was sent to those who wish it (95% for all).
- Evidence that each patient has a nominated consultant for their HIV (target: 95%).

- Evidence that there is provision of consultant advice and clinical supervision during routine outpatient working hours (target: 100%).
- Evidence of formal processes to identify patients who may have disengaged from care and evidence of efforts to re-engage these patients.

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3c. Anti-retroviral prescribing

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

Rationale

Antiretroviral drugs (ARVs) suppress viral replication at various stages in the viral lifecycle, but do 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 treatment with ARVs, 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 ARV pharmacology and drug interactions may impact on pre-existing conditions. Safe and effective prescribing of appropriate combinations of ARVs 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 ARVs 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 between 20% and 60% of people receiving ARVs in Europe and the USA are at risk of clinically significant drug interactions, yet UK physicians were only able to correctly identify two-thirds of these potential interactions. 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 (NICE guideline on medicines optimisation, 2015; NHS specialist pharmacy report on polypharmacy 2014; King's Fund report on Polypharmacy and medicines optimisation, 2013). Recommendations from these resources inform and are incorporated into our quality statements below.

Antiretroviral drugs continue 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 anti-retrovirals 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.

Quality statements

- ARVs should only be prescribed by an appropriately qualified practitioner (see Standard 3c). Medical and non-medical ARV prescribers should maintain prescribing competencies on a continuing basis with evidence of HIV-specific continuing professional development (CPD), and evidence of clinical Programmed Activities or equivalent relevant to HIV care allocated in the job plan.
- Antiretroviral therapy 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 (see Standard 3c).
- 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 self-reported adherence at each clinician visit assessed 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 antiretroviral regimens prescribed should be recorded in the patient's clinical records. This information, including reasons for previous treatment changes should be as accurate as possible.
- A drug history should be undertaken and documented each time ARVs are 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.
- A medicines optimisation/usage review should be undertaken by a HIV specialist pharmacist, at least annually where patients are on other medications. This should take into consideration adherence, any difficulties with medication and drug–drug interactions. This should be documented in the clinical records.
- All prescribers of ARVs should be able to readily access and regularly 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 HIV drug–drug interactions and for primary care to verify non-HIV-related prescriptions issued to people with HIV.
- HIV clinics should provide pharmacist- and nurse-led interventions, including outreach in the local community, to provide flexible care arrangements supporting antiretroviral therapy prescribing for patients who have difficulty attending formal clinic appointments.

- Persons in prisons or other detention facilities should have a regular and continuous supply of anti-retroviral medications alongside adequate access to 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 an adequate supply of medication to allow continued adherence while making their own arrangements for a further supply.
- HIV services and patient representatives should work in partnership with commissioners 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

Auditable outcomes

- Evidence of clinical appraisal of HIV therapy prescribers, which records participation in relevant CPD activities on HIV therapy.
- Proportion of patients who are new to treatment who are prescribed a treatment regimen in line with BHIVA guidelines (>90%) and who have a full clinical and psychosocial evaluation and assessment of “readiness” in line with national guidelines (>90%).
- Adherence documented within the first 3 months of starting antiretroviral treatment (ART) and at least annually thereafter (target: 95%, both)
- Patients starting or established on ART with HIV viral load and safety monitoring performed in accordance with national guidelines (target: 95%).
- Proportion of all patients who have a documented medication review in the past 15 months (97%).
- Proportion of patients who report that they were as involved as they wanted to be in treatment decisions (>90%).
- Evidence that patients are offered written information and access to peer support when making treatment decisions and in reporting side effects.
- The HIV service should be able to demonstrate that patients with virological rebound are rapidly recognised, and managed according to national guidelines.

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Consultation draft

4. Complex HIV care

4a. Inpatient care

People with proven or suspected complications of HIV infection 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 within an acute medical team supported by immediate and continued engagement with specialist HIV expertise and advice.

Rationale

People living with HIV who present with complications of HIV infection 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 6,095 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 1,000 compared to 3.6 per 1,000). 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 patients living with HIV has changed over the last decade. The use of effective antiretroviral therapy in people known to have HIV infection has led to fewer people requiring inpatient care for opportunistic infections and AIDS-related complications. 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 infection 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 protocols/formalised pathways for integrated care for those conditions requiring specialist input, such as lymphoma, multicentric Castleman disease, co-infection with hepatitis B and C, and end-organ liver and renal disease.

People with HIV 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 which 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 should have documented pathways to appropriate inpatient services. It is accepted that not all people living with HIV people with proven or

suspected complications of HIV infection require transfer to an HIV specialist unit and they may be cared for safely and effectively locally. They should, 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 should 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 guidelines for the treatment of HIV infection and its complications.

People living with HIV should expect that if they are 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 this will mean that their care will be discussed with the designated inpatient unit within the network.

Care pathways

People who need 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.

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, NMC code of conduct and national standards. People with HIV infection have the right to expect that their care is provided in a safe environment and that everyone is treated with dignity and respect regardless of race, sex 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.

Health care 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 who are living with HIV and who are admitted to hospital should be protected appropriately from nosocomial cross-infection. Service arrangements should be in place to reduce and avoid risk of nosocomial and cross-infection and to ensure immediate access to appropriate isolation facilities.

Care arrangements of HIV inpatient units

Arrangements for care in specialist HIV inpatient services should ensure there is:

- Provision of 24-hour access for acute care
- Co-location with high dependency unit (HDU) and intensive care 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 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
- Access to 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
- Access to a full range of on-site imaging services

Arrangements for care should ensure that access to the above services, advice and provision of results is not delayed and/or potentially impacts negatively on the quality of care provided and treatment outcome.

Measurable and auditable outcomes

- Proportion of all patients admitted within 24 hours of time of request for transfer (target 90%).
- Evidence that consultant physicians who have responsibility for the care of inpatients with HIV infection undertake regular and up-to-date continuing professional development (CPD) in both HIV medicine and general medicine, and have a job plan with designated PAs for inpatient care, the number of which should be appropriate to the unit workload and complexity of patients seen.
- Evidence that a specialist HIV inpatient service is able to provide 24-hour HIV specialist consultant cover for the management of HIV disease within a designated network where applicable.
- Evidence of existence of formal robust network arrangements appropriate to a geographical area to ensure that patients requiring inpatient care have equitable access to best-quality advice.
- Proportion of all patients admitted with AIDS-defining opportunistic infection/cancer still alive 30 days and 6 months after diagnosis.

- Proportion of all inpatients presenting with an AIDS-defining condition or serious bacterial infection and CD4 count <350 cells/mm³ started on, or maintained on, antiretroviral therapy within 12 weeks (target 95% 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 95%).
- Evidence of review of all deaths of HIV patients admitted to an inpatient unit.
- Evidence of patient survey to assess satisfaction regarding inpatient treatment and care in the preceding 3 years.
- Evidence of recording of clinical incidents, complaints and their investigation.

4b. Co-morbidities, co-infections and cancers

People with HIV should be able to access a comprehensive range of specialist services to manage co-morbidities, co-infections and cancers as required.

Rationale

Monitoring and treatment for people with HIV infection needs to be in accordance with current national guidance to maximise health and life expectancy and minimise morbidity and mortality. A combination of an aging HIV cohort, longer duration of HIV infection and long-term antiretroviral therapy has resulted in a shift from HIV associated pathology and ill health associated with severe immunosuppression to non AIDS co-morbidities associated with aging 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 infection. 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 pathways are established with local or regional specialist services to allow equitable access to care for people with HIV.

Primary care has an important role in the long-term management of HIV. Regular communication is strongly recommended due to the increase in non AIDS co-morbidities and the complexity of HIV drug-drug interactions to promote patient safety unless patients specifically refuse consent. Establishment of clear protocols and pathways for care between primary and secondary care are essential for safe delivery of service.

People living with HIV are at increased risk of certain co-infections, particularly tuberculosis (TB), hepatitis B and hepatitis C. Risk factors include immuno-suppression 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 with HIV infection 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 with HIV infection 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 multi-disciplinary team, including oncologists, HIV physicians and palliative care physicians where appropriate.

Co-morbidities

Quality statements

- People attending HIV outpatient clinics should undergo regular screening, as set out in the BHIVA guidelines for 'Routine investigation and monitoring of adult HIV-1-positive individuals' (2016), in order to detect cardiovascular, renal, liver, bone and other co-morbidities.

- People with HIV should have access to services to manage co-morbidities safely and effectively either within the HIV service or in collaboration with appropriate non-HIV specialist teams.
- Clear pathways should be developed to facilitate referral to local or regional services for those with complex and/or less common co-morbidities.
- People with HIV should have timely access to diagnostic tests required for the detection and investigation of co-morbidities.

Measurable and auditable outcomes

- Patients with a smoking history documented in the last 2 years (90%) and blood pressure (BP) recorded in the last 15 months (90%).
- Patients aged >40 years with 10-year cardiovascular disease (CVD) risk calculated within 1 year of first presentation (90%), and within the last 3 years if taking ART (90%).
- Documented assessment of renal function, to include assessment of proteinuria in the last 15 months (>90%).
- Bone fracture risk assessment in patients over 50 years of age and post-menopausal women within last 3 years (>90%).

Co-infections

Quality statements

TB

- People with newly diagnosed HIV infection should undergo full clinical assessment to exclude active TB.
- People with HIV from high and medium TB incidence countries should undergo testing for latent TB infection.
- Access to rapid TB diagnostic tests and drug sensitivity testing should be available. Best practice infection control should be in place and intensive contact tracing 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.
- People with HIV and rifamycin-resistant/MDR TB should be managed in conjunction with teams with expertise in the management of drug-resistant TB.
- People with HIV and TB co-infection should be managed according to BHIVA guidelines for the management of TB/HIV co-infection in adults (2017 – consultation draft).

Hepatitis B & C

- People newly diagnosed with HIV should be screened for immunity to hepatitis A and B.
- People newly diagnosed with HIV should be tested for co-infection with hepatitis B and C.
- Non-immune individuals should be offered immunisation for hepatitis A and B.

- People with HIV who are co-infected with either hepatitis B or C should be managed according to national guidelines (BHIVA guidelines for the management of hepatitis viruses in adults infected by HIV 2013).
- People with HIV who are co-infected with hepatitis C (HCV RNA positive) should be referred to a specialist viral hepatitis clinic for further investigation and treatment with directly acting antivirals (DAAs).
- People with HIV and cirrhosis should be referred to a hepatology clinic for long term monitoring and management.

Measurable and auditable outcomes

TB

- People with HIV from high and medium risk countries screened for latent TB (>90%).
- People with HIV diagnosed with active TB managed according to BHIVA guidelines (>95%).

Hepatitis B & C

- Hepatitis A, B and C screening on diagnosis or first clinic appointment (>95%).
- People with HIV who are non-immune to hepatitis A or B offered vaccination as per BHIVA guidelines (>95%).
- People with HIV co-infected with either hepatitis B or hepatitis C managed according to national guidelines (>95%).

Cancers

Quality statements

- All people with HIV and malignancy should be referred to centres with expertise in the management of these conditions.
- Management of people with HIV and malignancy should be in line with the BHIVA Guidelines for HIV-associated malignancies (2014)
- Clinical networks supporting regional centres of excellence for the treatment of both AIDS-defining and non-AIDS-defining cancers should be developed.
- People with HIV 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 section 7d).

Measurable and auditable outcomes

- Evidence of existence of formal robust network arrangements appropriate to a geographical area to ensure that people requiring specialist oncology services have equitable access to best-quality advice.

- Proportion of people with HIV and malignancy linked to specialist oncology services (96%)

Consultation draft

4c. Supporting people with increased needs

[This section is still in development and should be available for consultation by Monday 29th January. Please note that this section will include intimate partner violence]

Consultation draft

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 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. Regular (at least annually and more frequently for some depending on their risk) sexual history review and alcohol and recreational drug use history can identify those requiring additional clinical input.

Rationale

Good sexual health is part of good overall health. The impact of living with HIV, a potentially stigmatising sexually transmissible infection, that 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 require access to appropriate, culturally sensitive and effective information and support about sexual behaviour and minimising transmission risks. Practitioners need specific knowledge and expertise in this area to be able to sensitively discuss issues of great personal importance to those living with HIV and their partners, including sex and sexuality, safe sexual practices and the HIV and sexually transmitted infection (STI) risks of different sexual practices, HIV transmission risks in the context of effective therapy and preventative therapy for contacts, issues around HIV disclosure and fear of criminalisation. Guidelines produced by BHIVA, BASHH and the FRSN on the sexual and reproductive health of people living with HIV should be followed (<http://www.bhiva.org/SRH-guidelines-consultation.aspx>). Practitioners should be up to date on key emerging issues affecting sexual risks, such as chemsex and hepatitis outbreaks, and STEI and be able to counsel and support accordingly. Sexually transmitted infections are more common in people living with HIV. People living with HIV 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. Men who have sex with men (MSM) who are living with HIV have a higher prevalence of bacterial STIs including syphilis, viral infections including Hepatitis C infection and of emerging STIs such as Sexually acquired enteric infections (STEI). Lymphogranuloma venereum (LGV) is now endemic in the UK with men living with HIV disproportionately at risk. 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 current as well as emerging STI risks and outbreaks at their routine HIV appointments so they can identify the need for additional healthcare testing themselves. In the case of outbreaks it may occasionally be necessary to advise and recall prior to the next appointment.

Sexual health care should be primarily for the benefit of the individual, and the cornerstone of sexual health care 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 infection.

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 if sex occurred or will occur prior to the taking of effective antiretroviral therapy (and becoming undetectable), by ensuring sexual partners are aware of the presence of HIV within the relationship. Prevention strategies are key, including risk reduction counselling and antiretroviral medication, either as prophylaxis for negative partners (in the form of pre-exposure prophylaxis (PreP) or post-exposure prophylaxis following sexual exposure (PEPSE)), or treatment for the person living with HIV (treatment as prevention, TasP). Since the previous Standards, new evidence has emerged regarding transmission of HIV, showing that people living with HIV on antiretroviral therapy with an undetectable viral load in their blood (achieved and sustained for at least 6 months) 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. It is important to note that 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 in addition to prevent other STIs.

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

The need for testing of the children of parents living with HIV, irrespective of their age and health status, has been highlighted in *Don't Forget the Children* (<http://www.bhiva.org/documents/Guidelines/Dont%20Forget%20the%20Children/DFTC.pdf>), which provides the relevant guidance. 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. (ref Don't forget the Children CHIVA 2009) 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. 2012; http://www.gmc-uk.org/guidance/ethical_guidance/13257.asp). 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 be infected is a priority.

Quality statements

Sexual health

- Sexual health assessment should occur at least annually for people with HIV. Where the HIV service is separate from the sexual health service, people with HIV who require it should be actively facilitated to access local sexual health services at least yearly, to enable access to the full range of sexual health interventions in addition to screening.
- All those living with HIV should have easy access to investigation, diagnosis and treatment for STIs, in line with national guidance. Where this cannot be provided within the HIV service, agreed referral pathways to sexual health services should be in place, ideally with rapid access to facilitate testing and treatment.
- Syphilis serology should be included in the baseline investigations for people at the time of initial HIV diagnosis and at regular intervals according to risk thereafter (3–6-monthly or annually, depending on risk).
- Hepatitis A, B and C serology should be included in the baseline investigations for people at the time of initial HIV diagnosis and at regular intervals according to national guidance and risk, which for some will be 3 monthly.
- People living with HIV should be able to access preventative vaccines for hepatitis A and B, as well as other sexually transmitted infections, such as HPV, as they become available.
- People living with HIV should be made aware of the range of interventions which have been shown to reduce risk of onward HIV transmission, including evidence that effective antiretroviral therapy is associated with reduced rates of HIV transmission (TasP).
- People who are not on effective antiretroviral therapy (for whatever reason) or not yet undetectable should be made aware of the effectiveness of PreP and PEP for uninfected sexual partners according to risk factors.

Contacts at risk of HIV infection

- The HIV status of all children born to people living with HIV should be assessed for risks of vertical transmission, where children are defined as those who have not yet reached their 18th birthday.
- Testing children at risk of HIV infection should be discussed with at least one of the child's parents or legal guardians if the mother is living with HIV or her HIV status is unknown, and appropriate testing and follow-up organised with paediatric colleagues.
- All those living with HIV should be offered support and guidance with partner notification (PN) at the time of HIV diagnosis, and if HIV viral load is >200copies/ml whenever there are new partners whose HIV infection status is unknown. This should

be provided via sexual health services or within the HIV service by those with sufficient expertise.

- Patients should have the option of informing sexual partners themselves (patient referral) with support, or supplying information for a health worker to notify the partner anonymously (provider referral).
- Progress with PN should be re-visited regularly until resolved. Outcomes should be documented in the clinical record and audited annually against the BHIVA/BASHH HIV PN Standards or direct link depending what is decided for overall document.
- People living with HIV should be offered written and verbal information which is both culturally and age-appropriate about prevention of HIV transmission, including mechanisms for partners to access PrEP and PEPSE if relevant.
- People living with HIV at risk of onward transmission should be offered one or more one-to-one risk-reduction discussions based on a theory of behaviour change, such as motivational interviewing and/or a risk-reduction support group. This should also be offered to those at high risk of STIs.
- People with HIV should be aware of the importance of avoiding future STIs to which they may be more susceptible, and be more infectious to others in the context of underlying HIV infection.
- People who have been diagnosed HIV positive should be made aware of their legal position on HIV transmission, and how to protect themselves from prosecution.

Measurable and auditable outcomes

- Documented evidence in the clinical record that a full sexual history and sexual health screen has been offered within 4 weeks of an initial diagnosis of HIV, and annually thereafter (target: 90% of patients).
- Documented evidence in the clinical record of syphilis and hepatitis C screening within 4 weeks of diagnosis, and routinely thereafter depending on risk (3–6 monthly or annually) (target: 90% of MSM to have syphilis and hepatitis C screening at least once per year).
- Documented evidence of yearly consideration of offer to access to Sexual Health services where HIV services are separate.
- Documented evidence in the clinical record that all people are screened at initial visit and those identified to be susceptible to hepatitis A and B infection at initial HIV diagnosis are offered a course of vaccination.
- Documented evidence of PN discussion at time of diagnosis to determine if any at risk contact has occurred within previous 72 hours to identify and refer partners potentially eligible for PEP. (BHIVA/BASHH HIV PN Standard 4: 97% patients).
- Documented evidence that partners at ongoing risk are informed how to access PrEP/ PEP within 2 weeks of the first PN discussion. (target 90%).
- Documented evidence in the clinical record that partner notification has been discussed with people living with HIV within 4 weeks of receiving a positive HIV diagnosis, and

within 1 week of identifying subsequent partners at risk (BHIVA/BASHH HIV PN Standard 3: 97% of index patients.)

- Partner notification outcomes should be audited against the BHIVA/BASHH HIV PN standards:

Standard 1:

- 0.6 partners per index case verified tested within 3 months of initiating the PN process;
- 0.8 partners per index case reported or verified tested within 3 months of initiating the PN process.

Standard 2:

- 65% of contactable partners verified tested within 3 months of initiating the PN process;
- 85% of contactable partners reported or verified tested within 3 months of initiating the PN process;
- Documented evidence of risk-reduction discussion within 4 weeks of initial diagnosis, and within 1 week of subsequent risk disclosures. This should include discussion on the use of effective antiretroviral therapy to reduce risks of onward transmission (target: 90% of patients living with HIV).
- Documented evidence that people living with HIV who may be at risk of passing on HIV to others have been offered one-to-one risk reduction based on a theory of behaviour change, or access to an appropriate support group, within 1 month of diagnosis/risk behaviour being identified.
- Evidence of a patient experience survey to assess satisfaction regarding discussion around sexual health.
- Documented evidence that testing of children has been considered within 4 weeks of diagnosis for mothers with children where the mother's HIV status is positive or unknown irrespective of location of children (target: 90% of patients).
- Documented evidence that all children at risk currently in the UK have been tested within 6 months (target: 90%).
- Annual review to identify any additional children that may be at risk (target: 95%).
- Evidence of a patient experience survey to assess satisfaction regarding discussion around HIV testing of their children.
- Documented evidence that recreational drug use (to identify chemsex and other harms) and STI risks have been discussed at least annually in MSM and Trans individuals

References

1. BHIVA/BASHH/SSHA/NAT. (2015). HIV partner notification for adults: definitions, outcomes and standards.
2. CHIVA (2009) Don't forget the Children

3. BHIVA - BHIVA endorses 'Undetectable equals Untransmittable' (U=U ...
www.bhiva.org/BHIVA-endorses-U-U-consensus-statement.aspx
4. Risk of sexual transmission of HIV from a person living with HIV who has an undetectable viral load, Messaging Primer & Consensus Statement
<https://www.preventionaccess.org/consensus>

Consultation draft

5b. Reproductive health

People living with HIV should have access to safe, effective, and acceptable methods of fertility regulation, both for conception and contraception. Women living with HIV should be able to access expert advice and services to enable safe reproductive health: these include contraception, pregnancy planning and spacing, access to termination of pregnancy services (or referral and support to attend if services are unavailable) and specialist multidisciplinary obstetric services to ensure a healthy infant and mother. 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 acquisition 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.

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 antiretroviral (ARVs) means that women living with HIV can have a greater choice of contraceptive methods that do not interact with their ARVs (SRH guidelines).

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 antiretroviral therapy, and the couple should be counselled that the risk of transmission to the HIV-negative partner is effectively zero in this situation. In the era of routine recommendation of early ARVs for people living with HIV, and Treatment as Prevention (TasP), where the partner living with HIV is not on ARVs or not on fully suppressive therapy, this should be reviewed and ARVs offered and/or optimised as appropriate.

Pre-exposure prophylaxis (PrEP) for HIV negative partners of individuals 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 which have 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 post-natal care, results in rates of vertical transmission in the UK that are between 0.1% and 1%.

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 ten-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. 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 National Institute for Health and Care Excellence (NICE) menopause guidelines [ref]. 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
- Women living with HIV should have access to accurate information about the full range of contraceptives and pregnancy choices, including specialist advice on drug interactions for women using antiretroviral drugs. 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.
- Women 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 termination (where available), 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. Pathways should be in place for referral of couples with fertility issues or in need of assisted conception.
- All trusts with obstetric units need explicit pathways both to ensure the appropriate handling of HIV serology results identified through the antenatal screening programme and to enable women 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 would be:
 - Within 10 working days from the date of the initial HIV positive result: for an asymptomatic pregnant woman, 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 pregnant woman, 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 her expected delivery date
 - Immediately: for a pregnant woman newly diagnosed HIV positive or with a new reactive POCT (point-of-care test) in labour
- The management of pregnancy, childbirth and the immediate postnatal period for women living with HIV 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) with expertise in HIV and pregnancy. Designated individuals within a trust or network should be identified.
- Women living with HIV should have access to accurate information on the full choice of post partum contraceptives and these should be accessible immediately post partum.
- Provision of ARVs 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.
- All mothers known to be living with HIV should have access to the full range of interventions which have been shown to reduce the risk of onward HIV transmission, including 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 mothers 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.
- Women living with HIV should have access and/or referral to Peer Support as outlined in National Standards particularly during pregnancy

Measurable and auditable outcomes

- Proportion of women living with HIV with documented discussion of current reproductive choice and current contraception during a defined period (numerator: number of women of reproductive age with documented discussion during defined period; denominator: total number of women of reproductive age attending HIV service during defined period; target 90%).
- Services should be able to evidence an inclusive approach when assessing and providing conception desires and options e.g. annual review includes men
- Proportion of women living with HIV >45 years old with assessment of menopause symptoms (numerator: number of women > 45 years with documented discussion during defined period; denominator: total number of women >45 years attending HIV service during defined period; target 90%)
- HIV services should be able to demonstrate that they have care pathways for people who living with HIV to address contraceptive, conception, fertility and menopause needs.
- HIV services should be able to provide evidence that care plans, to be employed by the multidisciplinary team, are in place for women with HIV who are pregnant. The care plan should cover pre-, intra- and post-partum care and paediatric follow-up and should be available at the point of care.
- HIV services should be able to demonstrate that all pregnancies among women known to have HIV should be reported to NSHPC in accordance with existing arrangements.
- Evidence of a patient experience survey which includes satisfaction regarding discussion around reproductive health and conception options.

References

1. SRH guidelines
2. Menopause refs
3. Contraceptive refs
4. Faculty of Sexual and Reproductive Healthcare. FSRH Guideline Executive Summary: Contraception after Pregnancy. FSRH. January 2017
5. CHIVA Standards of care 2017
6. National Standards of Peer Support
7. <http://hivpeersupport.com>

6. Psychological care

People living with HIV should receive care and support which 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 by a turbulent political and economic climate, with reduced services and poor morale widely reported among people living with HIV and those who work with them. Language and terminology in this area can be confusing and controversial, with different words used by different groups. These Standards use the following terms:

- a) **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 etc.).
- b) **Mental health:** psychological and psychiatric issues given diagnostic labels such as anxiety, depression, post-traumatic stress, sleep problems, suicidal thoughts and self-harm, and substance misuse.
- c) **Cognitive functioning:** the neurological health of the brain and how this is expressed cognitively (memory, language, processing speed etc.) and how HIV, its treatment, and other health and lifestyle factors can sometimes affect this.

The Standard draws upon the Standards for Psychological Support for Adults Living with HIV (BPS, BHIVA & Medfash, 2011) 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).

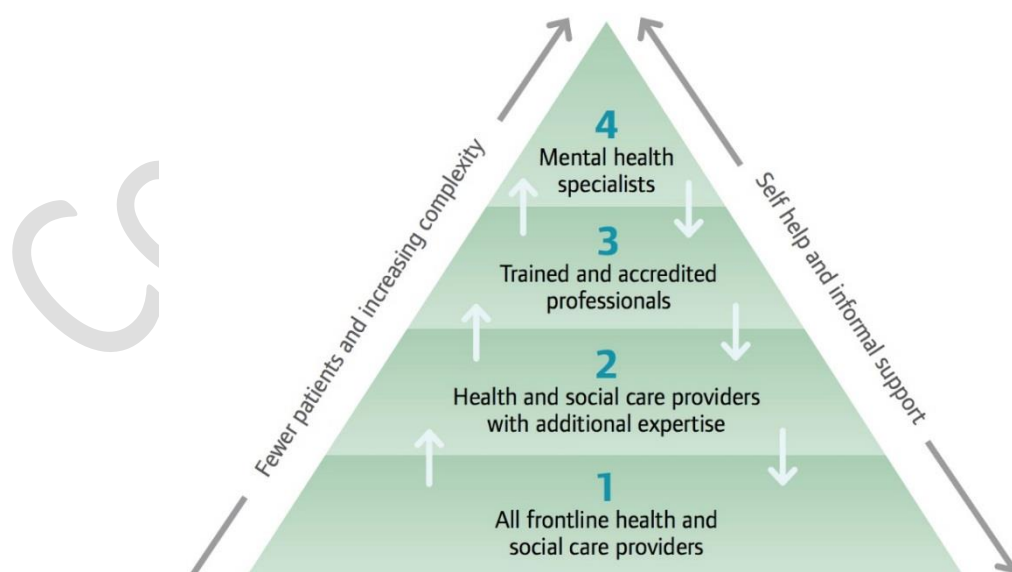


Figure 1. Stepped care model of Psychological Support for Adults Living with HIV (2011)

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 which are HIV-specific for common mental health difficulties (e.g. anxiety, substance abuse, 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, Dieticians, Physiotherapists, Psychiatrists, Occupational Therapists
Level 4	Specialist mental health services (including inpatient) for severe and enduring difficulties in which HIV is often not the central or only issue (e.g. psychosis, severe depression, suicidality, mania, eating disorders, personality issues); or neurocognitive assessment and rehabilitation	Multidisciplinary approach incorporating therapy and pharmacology: e.g. Clinical and Counselling Psychologists, Mental Health Nurses, Pharmacists, Psychiatrists, Occupational Therapists

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

6a. Emotional well-being

Rationale

“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.”

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 etc.). 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.

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 Index UK, 2009). 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 etc.). 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 (Lazarus et al., 2016).

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 an added psychosocial stressor.

Despite this, the majority of people living with HIV manage their physical and mental health and wellbeing 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 (Catalan, Ridge & Rosenfeld, 2017). 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 has 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

- People living with HIV should be asked about and supported with any stigma that they might have experienced or fear related to HIV (including self-stigma).
- The potential burden of living with and managing a chronic illness should be routinely monitored for people living with HIV.
- 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

- Documentation in clinical notes of discussion of potential HIV related stigma for all new patients, and referral to the appropriate level of support as required.
- Documentation in clinical notes 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).
- Documentation in clinical notes of discussion of peer support for all new patients, and sign-posting to appropriate services should the person living with HIV want.
- Clinical care pathway documentation includes peer support pathway options (in-house and/or external agencies).

6b. Mental Health

Rationale

Studies have found higher rates of depression, anxiety, post-traumatic stress, sleep difficulties, substance abuse, self-harm and suicidal thoughts and enduring mental health issues among people living with HIV compared to the general population. For example, Lowther et al., (2014) found in their systematic review among people living with HIV on HIV treatment the mean point prevalence of depression was 25.81%, and of anxiety was 21.53%, in high income countries such as the UK (see BPS et al., 2011 for further background).

The reasons for this are complex and include higher risk of HIV infections in people with pre-existing mental health difficulties, traumatic life events and substance misuse, and the impact of living with a stigmatised, chronic medical condition, with treatments that can potentially cause neuropsychiatric side-effects.

Not only does this negatively affect quality of life, but it can create a vicious cycle as these can complicate clinical care (e.g. disengagement from healthcare systems, non-adherence to antiretroviral medication), thus compromising physical health and heightening the risk of onward HIV transmission. However recent audits have found variability as to the extent to which mental health screening is conducted, and concerns regarding access to relevant mental healthcare services when detected (NHVNA, 2015).

Therefore the assessment, management and promotion of mental health for people living with HIV is of critical importance, and 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 antiretroviral therapy, 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 questions 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 health care, to minimise fragmentation, with the person living with HIV included in communication whenever possible.

Screening measures

Specific screening tools should not be seen as a replacement for an individual discussion about emotional well-being 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. However conversely being asked "How are you?" will not necessarily prompt a discussion of depression, anxiety, insomnia, cognitive issues, PTSD etc., and so 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 psychological support or psychiatric 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 not necessarily have an awareness that this could be improved with interventions. There can also be stigma associated with accessing mental health services (e.g. Henderson & Thornicroft, 2009), especially in some cultural groups such as black and minority ethnic (BME) communities and men, and so for these reasons people living with HIV may under-report their difficulties in consultations.

As such screening tools for mental health may be useful. It is understandable and laudable that many would like there to be standardisation of such screening measures nationwide. However, this is not currently possible due to the lack of evidence. As such 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 4.

Intervention

The precise management of the issue(s) present will depend on the severity and complexity of the mental health difficulty, evidence-base, and the person living with HIV'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 regards 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, for example mindfulness-based cognitive therapy and prevention of depressive relapse or recurrence (Kuyken et al. 2015; NICE, 2016). This paradigm is known within psychological therapies as the 'What works for whom' approach (Roth & Fonagy, 2013).

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

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 of these) 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, with timely assessment and management by qualified mental healthcare professionals as appropriate. This should include a review for any symptoms of: depression, anxiety, post-traumatic stress, sleep difficulties, substance abuse, self-harm and suicidal thoughts.

- Referral pathways between HIV and mental health services should be clearly defined, with clear and effective communication to coordinate care, and 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 issue(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), accessing research literature, training, supervision or consultation as necessary.

Measurable and auditable outcomes

- Documentation in clinical notes of annual screening for mental health difficulties, with referral to appropriate services as required (95%).
- Clinical care pathway documentation includes referral pathways for mental health assessment and management, and states if the services are HIV-specific.
- The mental healthcare professional working with someone living with HIV should evidence engagement with HIV-specific research literature, training, supervision or consultation.
- Clear documentation (e.g. letters, phone calls, emails) of communication between physical and mental health services, with the person living with HIV included if possible.

6c. Cognitive Function

Rationale

Cognitive disorders are difficulties with brain processing which 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 antiretroviral therapy. The prevalence of cognitive impairment in people living with HIV is challenging at the current time to ascertain, given several different diagnostic categories have been utilised. Based on less stringent criteria, up to 50% of people living with HIV are noted to have cognitive disorders, while based on more rigorous criteria, the prevalence is around 5-10% (Heaton et al., 2011; Su et al., 2015). 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 infection.

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 antiretroviral medication, and thus it should be assessed and managed. Furthermore, neuropsychological symptoms may be miss-diagnosed as mental health difficulties, or conversely mental health issues may be incorrectly attributed to neurocognitive health. Therefore, questioning for mental health 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 neurocognitive tests and batteries exist (Appendix A). None of these replace a full neuropsychological assessment but may be useful in cases where there are long waiting times. Some are generalist and some in theory 'HIV specific'; while relatively quick, cheap, and administrable by a variety of healthcare professionals (assuming appropriate training and supervision is provided) compromises are made regarding sensitivity and specificity, missing subtle or 'cortical' cognitive changes, and limited norms. As such screening tools should be selected based on what is most appropriate for each person living with HIV.

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 vs. battery driven), as well as available norms, experience of the assessor, if re-testing is planned, and what tests are available locally.

Neurocognitive rehabilitation strategies or services should be offered in the instance that HIV associated cognitive impairment is detected (alongside mitigation of other cognitive risk factors and neurological review), and be based upon a compensatory rather than restorative approach. If antiretroviral neurotoxicity is suspected as the cause of cognitive impairment then antiretroviral management may need to be reviewed.

Quality statements

- All people living with HIV should be questioned annually for symptoms of cognitive or memory decline.
- If cognitive functioning symptoms are reported then full neuropsychological assessment should be offered to the person living with HIV by a qualified practitioner.
- 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

- Documentation in clinical notes of annual questions regarding cognitive functioning, with referral to appropriate services as required.
- Clinical care pathway documentation includes referral pathways for neuropsychological and neurological review by qualified practitioners.

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7. HIV across the life course

7a. Young adults and adolescents living with HIV

Adolescents include all young people defined by WHO as those aged between 10 and 19 years, and young adults aged between 20 and 24 years. The BHIVA 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. https://www.chiva.org.uk/files/8015/0642/1695/CHIVA_STANDARDS_2017.pdf

1. Transition of care from paediatric to adult services

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 health care systems.” 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 program with a person centred individualised 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 to their age, developmental stage and social circumstances as they move from paediatric to adult care.

Quality Statements

- All adolescents living with HIV should have an individualised transition plan in line with national guidance
- Services caring for adolescents living with HIV requires 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

Measurable and auditable outcomes

- Documented evidence of having met the adult team prior to transfer from paediatric to adult care
- Documented evidence of a comprehensive medical and psychosocial summary of paediatric care
- Service named lead for transition in both paediatric and adult care

- Engagement in adult services measured by evidence of 2 visits within 12 months of referral

National Transitional Care Guidance

- Transition from children's to adults' services for young people using health or social care services, NICE guidelines [NG43] Published date: February 2016.
<https://www.nice.org.uk/guidance/ng43>
- Royal College of Paediatrics and Child Health (2003) The Intercollegiate Working Party on Adolescent Health. Bridging the gaps: health care for adolescents.
http://www.rcpch.ac.uk/system/files/protected/page/bridging_the_gaps.pdf
- You're Welcome quality criteria: Making health services young people friendly (2007)
<http://www.dh.gov.uk>
- CHIVA Guidance on transition
https://www.chiva.org.uk/files/2814/8587/2242/CHIVA_Transition_Guidelines2017.pdf

2. 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 1st 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 infection may have experienced bereavement or witnessed ill health in other family members. High rates of mental ill health 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 allowing a safe space to discuss HIV. It may provide support with adherence or to help escape isolation, particularly for young adults and adolescents living with HIV outside large cities where it can be accessed remotely, for example via Skype or facetime.

Quality statements

- 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, such as after college or work, and in easily accessible locations

- Feedback about the service should be actively sought from young, and should be acted on.
- Young adults and adolescents living with HIV should have access to mental health care 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 [ref CHIVA, Body and Soul etc]

Measurable and Auditable outcomes

- Compliance with “You’re Welcome” accreditation standards
- Documentation of annual mental health assessment and access to psychology services for young adults and adolescents living with HIV
- Documentation of discussion about peer support / number of young people accessing peer support

3. Sexual Health in adolescents

Young adults and adolescents living with HIV should have easy access to sexual healthcare and contraception services including the provision of LARC.

Rationale

Young adults and adolescents living with HIV are at high risk of unplanned pregnancies [ref Hypnet audit] 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 or mental ill health or substance misuse. Young adults and adolescents living with HIV should be regularly assessed for signs of sexual exploitation and other vulnerabilities. Proforma such as Spotting the Signs should be used with all under 18’s and any older adolescents felt to be at risk of child sexual exploitation (CSE). Recommendation: For those accessing a sexual health service, this should be undertaken at each attendance with a new problem or more frequently if vulnerabilities, or at least annually. For young adults and adolescents, those not initially at risk may become so, so practitioners should be aware of the risk factors, and how to assess, and undertake at least annually. 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 been victims of it or with particular vulnerabilities including learning disability above this age.

Quality statements

- Young adults and adolescents living with HIV should have access to sexual health and contraception services within clinic or direct referral pathways to these services.

- Young adults and adolescents living with HIV should be regularly assessed for signs of sexual exploitation and other vulnerabilities.
- Young people should be taught how to protect themselves and others from acquiring sexually transmitted infections. This should include discussions regarding antiretroviral treatment as prevention, including discussion that once the viral load is sustained at undetectable, there is effectively no risk of sexually transmitting the virus.
- Discussions should include indications for use of 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 implications of onward HIV transmission and how to protect themselves from prosecution.

Measurable and Auditable outcomes

- Documented assessment of sexual history and contraception status at each routine clinic visit (95%).
- Documented discussion around PREP and PEP (95%).
- Documented discussion regarding treatment as prevention (TasP), including risk of sexual transmission in the context of undetectable viral load (see Standard 5a).
- Documented discussion on legal implications for HIV transmission (see Standard 5a).
- Documented Use of Spotting the Signs or other CSE vulnerability check list in all under 18s at least annually (100%).
- Staff should be trained in recognition of CSE, how to use Spotting the Signs or a similar tool, and actions to take (100%).

4. Management of Antiretroviral therapy for young adults and adolescents living with HIV

Rationale

For all young adults and adolescents living with HIV, ART choices should be in accordance with BHIVA, CHIVA (<http://www.chiva.org.uk/guidelines/>) and Paediatric European Network for Treatment of AIDS (PENTA <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 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 their uninfected peers. 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 than their uninfected peers. Mental health issues frequently first present in adolescence/young adulthood. Young adults and adolescents living with HIV have increased rates of mental

health (MH) diagnoses compared to their peers. Avoidance of ART 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 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.

Quality Statements

- 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 B5701 and resistance assays allow, or with tenofovir alafenamide (TAF) as per NHS England guidance <https://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 ART agents associated with CNS toxicities is recommended.
- Regimens with high 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

- Documented evidence of discussion of alternatives to tenofovir in young adults and adolescents living with HIV
- Documented evidence of discussion of and assessment for potential CNS toxicities for young adults and adolescents living with HIV on efavirenz

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Consultation draft

7b. Early to middle adulthood

Rationale

These Standards for early to middle adult life refer to those aged between 25 and 65, and will include individuals diagnosed in childhood, adolescence or early adult life, and infected both perinatally and behaviourally. Young people are defined by the WHO as 'adolescents' when aged between 10 and 19 years, and 'young adults' when aged between 20 and 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 45-65 years and spans the period of reproductive health and maximal employment.

Individuals 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 infected perinatally had 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 infected perinatally will live with the long-term consequences of infantile HIV encephalopathy.

Most people of these ages however are diagnosed as adults. Due to the trend to earlier diagnosis and earlier antiretroviral treatment (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 which 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 (1), poverty, and immigration status. It is important that services are configured to meet the needs of individuals in these disparate categories and be sensitive to the fact that people move between non-complex and complex categories. Here, they will have enhanced care needs.

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 in place to support all people living with HIV (please refer to Standard 6).

Age related statistics for mental health include

- New mental health diagnoses often first arise in early adulthood. In the UK general population, on entering early adulthood young women are almost 3 times as likely as young men (26% v 9%) to have mental health problems with increased rates of self harm, bipolar disorder and post-traumatic stress disorder.
- Pregnancy and the post-partum period represents an additional increased time of risk especially for those with a pre-existing mental health condition.

- The prevalence for psychosis peaks at 35-44 years at 1% per annum, twice the adults' population rate.
- Suicide was the leading cause of death for women aged 20-34 and in men under 50, with rates in men increasing significantly over the last decade, peaking in those aged 45-59.
- More recently there has been a significant increase in the prevalence of mental health disorders in both men and women aged 55-64 years.
- 34% of men who have sex with men (MSM) aged 35-54 years reported chemsex, compared to 20% aged 18-34 and 19% over 55, with use more common in London versus outside London (37% versus 17%). Chemsex was reported in 38% of men also reporting depression or anxiety versus 24% who had neither, and 39% of men who smoked versus 24% who did not.

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

Employment and housing are critical factors which will 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 (2).

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.

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 between 25 and 65 years education, training and employment are key elements of health and wellbeing. It's important that the impact of HIV on these is assessed especially at critical points such as first diagnosis, ART commencement, in-patient 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 individuals 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.
- Regular and timely access to peer mentors is an important way to supplement and broaden the support that can be provided
- 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 individuals need to take off work to undertake their routine care. Important features of such care for stable patients includes six monthly visits (including six 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 individuals 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
- Psychological disorders in these age groups are common. The mental health needs of people living with HIV should be screened annually, especially for symptoms of mood disorder and substance misuse.
- Referral pathways between HIV and mental health services should be clearly defined, with clear and effective communication to coordinate care, and the people living with HIV included whenever possible.
- Significant numbers of people aged between 25 and 65 undertake frequent work-related travel. For a proportion of these people, single tablet regimens (STRs) will offer considerable advantages especially where travel is to countries where people with HIV suffer discrimination or criminalisation. STRs should be available where it has been assessed that they provide such an advantage.
- Similarly, STRs should be one option available for individuals living at home or with friends where they have not disclosed their HIV status.
- 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 individuals supported to modify behaviours which improve their health. Support will range from providing information through to short interventions (eg motivational interviewing), and referral to specialist services (eg smoking cessation, drug and alcohol services).
- Other aspects of preventative health care are a key component of care and should be integral to routine follow-up. This includes vaccination (eg flu, pneumovax, hepatitis A and B, HPV), risk factor assessment and modifiable risk factor management (eg cardiovascular disease, bone, cervical dysplasia)
- Services should support individuals to have a healthy and fulfilling sex life. One key to this is the explanation of, offer and provision of treatment as prevention. People living

with HIV should expect the same access to quality reproductive, preconception, fertility and antenatal services as their HIV negative counterparts (BHIVA guidelines)

Measurable and auditable outcomes

- All HIV services should be linked to specialist HIV support services and these pathways should be described and available for service users (target 95%)
- All HIV services should be linked to drugs and alcohol support services and these pathways should be described and available for service users (target 95%)
- All HIV services should be linked to mental health services and these pathways should be described and available for service users (target 95%)
- Documented evidence of annual mental health screening in clinical case notes.
- Target as per BHIVA guidelines
- Length of time from referral to first appointment for mental health services.
- All HIV services should be linked to reproductive and sexual health services and these pathways should be described and available for service users (target 95%)
- Discussion of role of ART in reducing risk of onward HIV transmission (TasP) (target 95 or 97%)

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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 infection 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 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 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. Terrence Higgins Trust is currently developing work in this context. 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/information are relevant and acceptable – not all older adults will be as familiar with online resources as younger people.

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 service providers. Proactive screening for and identification of potential co-morbidities according to national guidelines (cardiovascular risk, osteoporosis, breast cancer screening, prostate cancer screening etc.), encouraging smoking cessation, and facilitating access to

active lifestyles will be important for people who are ageing with HIV, but is essential that this not lead to a hyper-medicalisation of people living with HIV.

Complex HIV care

There is considerable complexity around co-morbidities 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 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 number of clinic visits and lessen potential for harm; HIV pharmacists, older age pharmacists, physiotherapy, occupational therapy. Supplementary tailored health programs, for example, around exercise, may be 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 antiretroviral treatment (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 sub-optimal 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.

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 to sexual health services. Older adults are less likely to use condoms where there are no concerns about pregnancy and may have come out of 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 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 (for example 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 aging 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 had 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 co-morbidities (HIV, primary and secondary care providers), particularly as they relate to ageing with HIV.

There is clear need for ongoing high quality clinical and social research into the issues of aging in people living with HIV. Priority areas include the clinical impact of long term co-morbidities, optimal models of integrated care, residential and home-based care provision and managing age-related dementia for people living 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.

Rationale

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”[13]. 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[14]. 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 health care 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[15-18].

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[19]. 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 antiretroviral therapy has greatly increased life expectancy for people with HIV, it is essential that we continue to provide the skills of palliative care for 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[20]. Although most people would choose to know about their poor prognosis and to die at home[21-23], people with HIV are more likely to die in hospital than people dying from other conditions such as cancer[24].

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 care services should follow existing recommendations to provide men who have sex with men (MSM) with appropriate care[25, 26]. Good palliative care may also improve the bereavement outcomes of their significant others[27]. For patients of African heritage, cultural differences in the acceptance and the patient’s interpretation of pain[28-30] should be taken into account to avoid under-treatment.

Given the additional aspects of stigma and confidentiality for people 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.[31] Given the high prevalence and burden of pain (including neuropathic pain) and other symptoms among people living with HIV who are accessing treatment[7], the detailed assessment and management of these problems should be stressed.

Quality statements

Communication

- Information should be shared in a manner at 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[32])
- 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 is needed on who should be involved in care planning and provision in the case of reduced capacity. The Mental Capacity Act 2005 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 in capacity and the Mental 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 infection (as a serious communicable disease) must be disclosed on the death certificate if it contributed to the death (https://www.gmc-uk.org/guidance/ethical_guidance/30625.asp).

Auditable actions and outcomes

- Regular implementation of the Integrated Palliative Outcome Scale to monitor patient-centred outcomes (as recommended by the Committee of Ministers of the Council of Europe (Rec 23 2004) as a tool for strengthening palliative care across Europe) for ≥90% of patients with life limiting illness (either self-report or proxy-report) freely available at www.pos-pal.org
- File record of having had a conversation regarding prognosis for ≥90% of patients with life limiting illness
- File record of patient preferences for end of life care for ≥90% of patients with life limiting illness
- Advance Care Plan /Advance Directive on file for ≥90% of patients with life limiting illness
- Achieved place of care for majority of the last 90 days of life for ≥90% of patients with life limiting illness
- Evidence on IPOS of pain control at 1 or 2/5 at end of life for ≥90% of patients with life limiting illness
- Evidence on IPOS of symptoms control at 1 or 2/5 at end of life for ≥90% of patients with life limiting illness
- Clear and agreed plans for emergencies and admissions for ≥90% of patients with life limiting illness

Further resources

The Palliative Adult Network Guidelines <https://www.amazon.co.uk/Palliative-Adult-Network-Guidelines-Fourth/dp/B06XS7M14W>

Clinical guidelines on palliative and supportive care for people with HIV/AIDS <https://careacttarget.org/library/clinical-guide-supportive-and-palliative-care-people-hivaids>

The Palliative Outcome Scale www.pos-pal.org

The 5 priorities of care <https://www.cqc.org.uk/news/stories/priorities-care-part-new-approach-care-dying-people>

UK End of Life Care Strategy <https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life>

“Route to Success” in end of life care <http://endoflifecareambitions.org.uk/route-to-success/>

UK recommendations for palliative and end-of-life care for LGBT people: <https://www.kcl.ac.uk/nursing/departments/cicelysaunders/research/living/access/index.aspx>

The Mental Capacity Act 2005 <https://www.nhs.uk/conditions/social-care-and-support/mental-capacity/>

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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 healthcare workers have a 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 reproductive, psychological and sexual health. There is a two-way interplay between HIV infection 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 and that the MDT have the appropriate competencies to undertake this care safely and effectively. 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 required by a person with HIV 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, working in services appropriately equipped to provide these specialist and non-specialist services.

In order that people living with HIV have full and timely access to high quality care it is also essential that non-specialist healthcare 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 (1). Such training should also include the principles and practice of confidentiality, data protection, equality and diversity.

Quality statements

- Provision of HIV care should be a recognised activity at the Trust/organisational level. There should be clear lines of accountability through appropriate clinical networks.
- HIV remains a stigmatising condition that disproportionately affects people who often are already vulnerable. For example, because of single or combined factors relating to gender, sexuality, age, race, income, education or medical and social history. All staff in HIV services should have appropriate training regarding the diversity of affected communities and important social influences.

- People who are living with HIV should experience care that is delivered to the highest standards of confidentiality, privacy and dignity, in line with professional and regulatory guidance and national standards.
- Ensuring healthcare workers have core knowledge about HIV is a key element in combatting stigma within the NHS and it is recommended this teaching is included in the mandatory training undertaken by all employees.
- 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.
- Health care professionals should be supported to disseminate their expertise through teaching, training and sharing of best practice.
- Curricula are an important structural component of training. Meaningful involvement of people living with HIV in the development of these, particularly the specialist training curricula, is recommended.

Medical team

HIV specialists

The HIV-related competencies required for Genitourinary Medicine (GUM) speciality trainees to complete training are outlined in the syllabus of the Joint Royal Colleges Post-graduate Training Board (JRCPTB) GUM curriculum (2016) (www.jrcptb.org.uk). The learning objectives are the following:

- HIV testing and diagnosis
- Epidemiology, natural history, and general management of HIV1 and HIV2
- HIV prevention
- Complications of HIV (including opportunistic infections, malignancies, non-infectious conditions)
- Antiretroviral therapy (ART)
- Viral hepatitis co-infection
- Psychosocial aspects
- Sexual and reproductive health (including mother to child transmission)

For infectious disease (ID) specialists the 2014 ID curriculum (www.jrcptb.org.uk) details the competencies required to manage patients with HIV infection.

Specialist knowledge of these areas is required for the management of HIV, and therefore consultant physicians overseeing care should be competent in these areas. The Diploma of HIV Medicine (Dip. HIV Med.) is now compulsory for GUM trainees to complete specialist training and to enter the General Medical Council register of specialists. The 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

The Dip. HIV Med. was introduced in 2004 and hence most specialists now hold this qualification. The syllabus within the GUM curriculum can act as a useful resource for appraisal and revalidation. During appraisal (to be completed annually), HIV-specific continuing professional development (CPD) should be assessed and this should be further reviewed during 5-yearly revalidation.

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 two 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 with HIV, or who undertake care of people with complex comorbidities or coinfections, 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 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) (2) 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) (3)

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, for example, a district nurse.

The process of assessment of competence will be locally determined and should be multi-faceted including, for example, direct observation and reflective practice. Assessment should be part of appraisal, objective-setting and personal development planning and should be based on the NHIVNA competency framework.

Nurses are required by the Nursing and Midwifery Council (NMC) to undertake Revalidation and record 35 hours of continuing professional development (20 hours of which should be participatory) over 3 years to retain their registration. Learning opportunities for specialist nurses are: NHIVNA on-line training and CPD articles (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 antiretroviral therapy

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 (OTC), herbal and recreational drugs. They should have current appropriate knowledge and skills and be appraised annually. They should complete mandatory CPD entries each year in line with the General Pharmaceutical Council to fulfil continuing fitness to practice (CFTP) requirements and retain registration. A proportion of these entries should be in HIV-related areas or associated comorbidities reflecting the proportion of their role in HIV clinical care.

In addition, any requirements of competency assessment with the HIV Pharmacy Association (that may include a credentialing system under development with the Royal

Pharmaceutical Society) should be met. Sole practitioners should be part of a wider, professional network.

Competency to prescribe antiretroviral therapy (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 (4). 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) (5).

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 of safeguarding for vulnerable adults. Organisations or groups providing peer support should provide peer supporters with regular structured support, supervision as well as ongoing professional development.

Young people should have access to peer support, and organisations or groups providing this should have knowledge of, and procedures in place, for safeguarding and legal requirements for working with young people including consent for minors.

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 or senior-level skills in neurological, respiratory and musculoskeletal practice, while occupational therapists and speech and language therapists should have advanced or senior-level skills in neurological practice and in particular neurocognitive assessment and treatment. Therapists working in HIV specialist settings should also be able to demonstrate HIV-related continuous professional development activity such as completing an on-line HIV rehabilitation module.

Dietetics team

Specialist dietetic input should be provided by registered dietitians (RDs) 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 DHIVA Dietetic Competency Framework (ref 6). 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 Health Professions Council to maintain an accurate record of their CPD activities. The HIV specialist dietitian should include a proportion of these activities in HIV-related areas and associated comorbidities, and ensure that their CPD has contributed to the quality of their practice and service delivery within the HIV MDT.

Measurable and auditable outcomes

- Proportion of appraisals that include evidence of HIV CPD
- Proportion of providers with key HIV information within mandatory training
- Trainees and students working within an HIV service (all professions): named supervisor and evidence of supervision of safe and competent HIV practice.

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5. National Standards for Peer Support in HIV (2017) available at <http://hivpeersupport.com/>

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 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. Audits involve systematic assessment of care and may be completed at the national, regional or local level.

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 individuals who die can be revealing and should include all deaths among individuals 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 that treatments are provided to people living with HIV, and the improvement of prevention, treatment, and outcomes for people living with HIV.

Commissioning

Commissioners need data to be able to plan and commission HIV services safely. All HIV services should be able to provide data in line with commissioning requirements. Patients should expect that the HIV treatment and care they are receiving is from a service that is appropriately commissioned on the basis of needs assessment, adherent to national service specification and monitored so that they have some assurance of quality. In view of the complexity of HIV and the range of care services required, commissioners should work together to plan provision across the care pathway, and should actively seek involvement of people living with HIV.

Quality statements

- All providers of NHS HIV care (which may increasingly include independent providers) should take part in relevant national and local audit, quality improvement projects,

service reviews and applicable research studies. Where taking part in a research studies, data should be provided in a timely manner, as agreed with study investigators.

- All providers of NHS HIV care should review deaths and serious incidents, which may include late HIV diagnoses, in accordance with current policy frameworks.
- All 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

Service providers should demonstrate:

- They provide information for local and national audits
- They conduct and participate in reviews of deaths, late diagnoses and other serious incidents
- They undertake quality improvement activities in response to outcomes of HIV-related audit and/or review.
- They are aware of HIV-relevant research within the NIHR research portfolio and elsewhere, are actively involved in research that is appropriate to their patient population, and that mechanisms are in place to alert patients to relevant research programmes.

8c. Public health surveillance, confidentiality and information governance

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

People with HIV should be informed and given choices about how their personal clinical information is shared with clinicians involved in their overall care outside of 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, anonymized and pseudonymised information are bound by strict information governance policies and confidentiality rules.

Public Health Surveillance

Data collected locally are sent securely to Public Health England (PHE) or Health Protection Scotland 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 antiretroviral treatment (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 (eg 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, should 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) 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.

Consent for information sharing, implied or explicit, is only valid if the patient understands what data is stored and who can access their information.

Within the HIV clinic, implied consent is assumed for data sharing within the multi-disciplinary team and for sharing data across teams for referral to GP or specialists. Patients can explicitly refuse consent to share information with teams that provide direct care. 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.

HIV patient should be informed about how their personal medical information is stored and shared outside of the HIV service and explicit consent may be required to share this information with other health professionals.

Information governance

At all levels, identifiable or potentially identifiable data should 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, this includes National Information Governance Board (NIGB) approval under section 251 of the NHS Act 2006 for Public Health England to collect patient-identifiable information without consent; this will be directly transferred to PHE. All staff within the PHE 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 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

Everyone registered with the NHS in England and Wales has their own unique NHS number, which facilitates the safe, efficient and accurate sharing of patient information, which is, in turn, an important factor in minimising clinical risk. Similar systems using the CHI (Community Health Index) number and HCN (Health and Care Number) are used in Scotland and Northern Ireland. As the delivery of health care becomes increasingly shared across a number of NHS clinical areas and providers, so the effective linking up and flow of information related to a patient becomes ever more important. Use of the NHS/CHI/HCN

number in HIV services offers a number of advantages for understanding service use, planning service development and joining up the various elements of care within the patient pathways and across providers. As HIV testing and diagnosis and care for the increasing range of co-morbidities expands across all sectors of the health economy, the NHS/CHI/HCN number is already known for many people living with HIV and its use is increasingly relevant for continuity of safe care. As pathways of care involve multiple service providers and commissioners, consistent use of the NHS/CHI/HCN number has great potential to be an effective tool to reduce clinical risk in HIV health care.

HIV stigma and prejudice continue to blight the lives of many people living with HIV, making confidentiality of clinical and personal details of paramount importance. However, confidentiality is not the same as anonymity. On balance, the clinical benefits of using a single identifier across all health services outweigh the risks and we suggest that the continued practice of not using the NHS/CHI/HCN number in some HIV services should be reviewed. In order to satisfy anxieties this may provoke, we therefore recommend a broad and transparent consultation on the use of NHS/CHI/HCN numbers in HIV care with the aim of developing clear guidance to help both staff and patients understand the issues involved.

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. 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 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 should be held securely and according to information governance standards and the law.
- All HIV service providers should have robust information systems with dedicated data-management staff to ensure accurate, complete and up-to-date information.
- All 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.

- All HIV services should follow robust information governance and confidentiality policies and gain patient consent for sharing personal identifiable clinical information outside of HIV services with other professionals involved in the care of the individual patient

Measurable and auditable outcomes

Evidence from Public Health England or Health Protection Scotland that services have provided:

- 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 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

Service providers should demonstrate 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 and / or applicable.

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12. Your healthcare records, NHS England
<https://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/overview.aspx>

Appendix 1

[References – to be compiled]

Consultation draft

Appendix 2

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 were contacted to request input and feedback.
- Drafting the rationale, quality statements and appropriate outcome measures for each standard. Working 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 further amended in the light of feedback received.

[Contributors to be included]

Appendix 3

List of outcomes and indicators in the NHS Outcomes Framework for 2017/2018: potential links to 2018 BHIVA Standards by domain

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 & 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, 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 & 4a](#)

Enhancing quality of life for carers

2.4 Health-related quality of life for carers (ASCOF 1D**) - [link to 2c & 4c](#)

Enhancing quality of life for people with mental illness

2.5 i Employment of people with mental illness (ASCOF 1F** & 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 & 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 & 7d](#)

5b Severe harm attributable to problems in healthcare – [link to 1a, 2b/c, 3a, 7c & 7d](#)

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

Consultation draft

Appendix 4

Potential screening measures

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 ½ the days/3=Nearly every day

Kroenke, K., Spitzer, R. L., Williams, J. B., Monahan, P. O., & Löwe, B. (2007). Anxiety Disorders in Primary Care: Prevalence, Impairment, Comorbidity, and Detection. *Annals of internal medicine*, 146(5), 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 ½ the days/3=Nearly every day

Kroenke, K., Spitzer, R. L., & Williams, J. B. (2003). The Patient Health Questionnaire-2: validity of a two-item depression screener. *Medical care*, 41(11), 1284-1292.

Neurocognitive 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?)

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Neurocognitive Screening Measures – Generalist

- Montreal Cognitive Assessment (Nasreddine et al., 2005)
Nasreddine, Z. S., Phillips, N. A., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., ... & Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society*, 53(4), 695-699.

- Mini Mental State (Folstein, Folstein & McHugh, 1975)
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- Addenbrooke's Cognitive Examination - Third Edition (Hsieh et al. 2013)
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Neurocognitive Screening Measures – Computer based

- Cogstate (Maruff et al. 2009)
Maruff, P., Thomas, E., Cysique, L., Brew, B., Collie, A., Snyder, P., & Pietrzak, R. H. (2009). 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. *Archives of Clinical Neuropsychology*, 24(2), 165-178.
- CANTAB (Sahakian et al., 1995)
Sahakian, B. J., Elliott, R., Low, N., Mehta, M., Clark, R. T., & Pozniak, A. L. (1995). Neuropsychological deficits in tests of executive function in asymptomatic and symptomatic HIV-1 seropositive men. *Psychological Medicine*, 25(6), 1233-1246.

Neurocognitive Screening Measures – HIV related

- HIV Dementia Scale (Power, Selnes, Grim & McArthur, 1995)
Power, C., Selnes, O. A., Grim, J. A., & McArthur, J. C. (1995). HIV Dementia Scale: a rapid screening test. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 8(3), 273-278.
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Appendix 5

[Glossary – to be compiled]

Consultation draft