



British HIV Association

Standards of Care for People Living with HIV 2013

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in partnership with

British Association for Sexual Health and HIV (BASHH)

British Infection Association (BIA)

British Psychological Society (BPS)

Children's HIV Association (CHIVA)

Dietitians working in HIV/AIDS (DHIVA)

Faculty of Public Health (FPH)

Health Protection Agency (HPA)

HIV Pharmacy Association (HIVPA)

Local Government Association (LGA)

National HIV Nurses Association (NHIVNA)

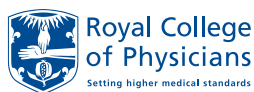
Rehabilitation in HIV Association (RHIVA)

Royal College of General Practitioners (RCGP)

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Royal College of Physicians (RCP)

Social Care Institute for Excellence (SCIE)



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British HIV Association

Standards of Care for People Living with HIV

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■ Contents

Foreword.....	II
Acknowledgements.....	V
Introduction and background	1
12 Standards of Care for People Living with HIV	
Standard 1: HIV testing and diagnosis	9
Standard 2: Access to, and retention in, HIV treatment and care	13
Standard 3: Provision of outpatient treatment and care for HIV, and access to care for complex comorbidity.....	19
Standard 4: Safe ARV prescribing: Effective medicines management	25
Standard 5: Inpatient care for people living with HIV	29
Standard 6: Psychological care.....	35
Standard 7: Sexual health and identification of contacts at risk of infection	41
Standard 8: Reproductive health	47
Standard 9: Self-management	51
Standard 10: Participation of people with HIV in their care	55
Standard 11: Competencies	61
Standard 12: Information for public health surveillance, commissioning, audit and research.....	69
Appendix 1: References.....	74
Appendix 2: The NHS Outcomes Framework.....	81
Appendix 3: Glossary of terms and abbreviations.....	84
Appendix 4: Contributors	91

■ Foreword

The British HIV Association (BHIVA), working in partnership with care providers, professional associations, commissioners and people living with HIV, has produced a set of quality standards for the care of people with HIV in the UK. They cover 12 key themes, prioritised as being the most important issues for the care of people with HIV. Derived from the best available evidence, the Standards focus on aspects of care that have particular relevance for delivering equitable high-quality services that secure the best possible outcomes for people with HIV.

■ Why has BHIVA developed these Standards?

In the three decades since the identification of HIV, progress in treatment and care has been enormous, with substantial improvements in both clinical outcomes and the lives of people living with HIV. Treatment outcomes for people with HIV in the UK are amongst the best in the world, which, despite current financial pressures, must be sustained and enhanced as new structures emerge within an evolving NHS. The Standards provide a reference point against which to benchmark the quality of HIV care. This will be especially important as new providers and commissioners enter the health economy 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?

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

For those with responsibility for the commissioning of services that will affect people with HIV these new Standards will be a critically important resource, as innovative and informed commissioning decisions will be required to meet the growing need for more efficient and cost-effective services. The Standards will be an important information source for the new policy and commissioning framework for HIV-related services at national and local levels, including the national HIV service specification that is in development with the National Clinical Reference Group and the payment-by-results

system of currency and tariffs for HIV treatment and care.

People with HIV should expect to have equitable access to consistently high-quality care no matter where they live. The Standards will inform people with HIV, their carers and those who advocate on their behalf about the care that people should expect to be able to access.

■ What do the Standards cover?

The Standards cover the range of care needed by people with HIV from the time they first receive a diagnosis of HIV. Standard 1 (HIV testing and diagnosis) 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. Following a diagnosis of HIV, it is essential that people are able to access (and be retained in) specialist HIV care, highlighted in Standard 2 (Access to, and retention in, HIV treatment and care).

As people with HIV live longer, their health needs change, and both the numbers of comorbidities and the complexity of prescribing for multiple health conditions increases. Standards 3 and 5 focus on key aspects in the delivery of high-quality outpatient and inpatient care for HIV services, ensuring that all people have equitable access to high standards of care wherever they live.

People with HIV need to be confident that appropriate systems are in place to ensure that ARVs are prescribed and monitored safely (see Standard 4, Safe ARV prescribing: Effective medicines management). Within Standard 4 there is a further commitment for HIV services and patient representatives to work in partnership with commissioners to develop strategies that facilitate cost-effective prescribing.

Dealing with issues of disclosure (e.g. to new sexual partners, those who may have been at risk of inadvertent exposure to HIV infection, and other health care professionals) is far from easy and can take its toll on psychological and emotional well-being. Standards 6 and 7 recognise the importance of providing care that promotes the mental, emotional and cognitive well-being of people living with HIV, and covers the important and complex area of disclosure to, and testing for, potential contacts of infection.

Standards 7 and 8 are about supporting people with HIV in establishing and maintaining healthy sexual lives for themselves and their partners, and ensuring high-quality reproductive and family health. Living well with HIV for the long term calls for strong self-management skills, education and engagement with peer support

(Standard 9), together with participation in decisions about all aspects of treatment and care, service design and delivery (Standard 10). People living with HIV should expect to be treated by health care professionals who are up-to-date and fit to practise safely. Standard 11 sets out the competencies that may be involved with delivering care for a range of practitioners.

Some of the key learning that has driven quality improvements in the care of people living with HIV has been derived from national surveillance data, audit and research. Standard 12 places a duty on all HIV services to maintain data security and to contribute information to maximise understanding of the HIV epidemic in the UK.

We are at a point where there is a real possibility that people with HIV can look forward to a life expectancy that approaches that of the general population. 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 in transforming these aspirations into a reality for people living with HIV in the UK.

Professor Jane Anderson, Co-Chair

Dr Simon Edwards, Co-Chair

■ Acknowledgements

The project partners are grateful for the support and guidance of all the members of the Standards Working Group. Particular thanks go to those members who gave their time, energy and expertise to the drafting and redrafting of substantial sections of the document: Dr David Asboe, Mr Simon Collins, Dr Valerie Delpesch, Dr Martin Fisher, Dr Stuart Gibson, Professor Saye Khoo, Dr Nicola Mackie, Dr Adrian Palfreeman, Dr Karen Rogstad, Mr Paul Ward, Dr Ed Wilkins and Dr Ian Williams. Without their enthusiasm, dedication and expertise, this publication would not have been realised.

We are delighted that so many community groups contributed to the production of the Standards. The working group had representation from UK-CAB and the Terrence Higgins Trust. Contributions to the writing groups came from: National AIDS Trust, Body & Soul, Forum Link, National AIDS Manual, HIV i-Base, North Yorkshire AIDS Action, Positively UK and the Monument Trust. There was also significant community representation and input to the two “HIV care in 2012” workshops in London and Manchester from: Positively UK, George House Trust, the African Health Policy Network, Leicestershire AIDS Support Services, Terrence Higgins Trust, Baseline, National AIDS Manual, THRIVINE, National AIDS Trust, The Sophia Forum and Positive East. Community feedback on the post-public consultation draft was extremely helpful. More detailed information on contributions to the 2013 Standards is contained in Appendix 4.

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

Thanks are due to all the individuals and organisations that took the time to respond to the on-line public consultation on the draft standards and/or attended the stand at the BHIVA conference in Birmingham to give useful feedback and advice. We are indebted to the following people who provided expert technical and editorial support to the project team: Dr Hilary Curtis (on behalf of the BHIVA Audit and Standards Subcommittee), Professor Margaret Johnson, Ms Claire Foreman of the London Specialised Commissioning Group and the BHIVA Secretariat at Mediscript.

We also extend our thanks to Sir Muir Gray and his team at NHS Right Care (QIPP), who jointly hosted the two “HIV care in 2012” workshops, providing focused support and impetus to the project at an early stage.

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

BHIVA Standards of Care project team

Professor Jane Anderson, Co-Chair

Dr Simon Edwards, Co-Chair

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■ Introduction and background

■ Introduction

In the UK, 30 years since its identification as the causative agent of Acquired Immune Deficiency Syndrome (AIDS), HIV continues to be a highly significant clinical and public health issue. 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

Best estimates suggest that over 100,000 people in the UK are living with HIV in 2012. About a quarter have not had their HIV diagnosed and are unaware that they are HIV positive (HPA 2011).

High rates of newly acquired HIV continue to be reported. In 2011 6280 people were newly diagnosed HIV positive, almost half of whom were men who have sex with men and almost one-third women. Effective antiretroviral therapy (ART) reduces morbidity and mortality and increases life expectancy. In consequence, the overall numbers of people with HIV in the UK are increasing year on year. Some 69,400 people living with diagnosed HIV infection were cared for by NHS HIV clinical services in 2010, with very high levels of retention in care. Over 1300 pregnancies were reported in women living with HIV in 2010, with at least 98% of babies being born without HIV infection.

Despite these advances, late presentation of HIV continues to carry significant risks of morbidity and mortality, reduced life expectancy, and increased rates of hospitalisation. Fifty percent of people newly diagnosed with HIV in 2010 presented at a late stage of infection with a CD4 count below 350 cells/mm³ (after the recommended time to start therapy). 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. Broadening HIV testing and diagnosis throughout clinical and community environments within high prevalence areas has been shown, through DoH-funded work, to be both feasible and acceptable.

People with HIV are living into old age and older people are acquiring HIV, as they remain sexually active in later life. One-in-five adults accessing HIV care in 2010 was 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 people acquiring HIV, increased life expectancy for people living with HIV, greater use of antiretroviral drugs and health care services, and changing comorbidities has increased HIV-related expenditure in the UK. A combination of increasingly constrained resources and the varying needs of a changing population of people living with HIV requires HIV service delivery to evolve and meet these challenges. Within the current models of care in the UK, HIV treatment outcomes and retention-in-care rates are amongst the best in the world, 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 2013

In 2007 BHIVA, in collaboration with other interested organisations, developed the first set of standards for clinical care for adults with HIV infection in the NHS. In the ensuing 5 years there have been significant changes in the field of HIV as well as in the commissioning and financial environment. Changes to the structure of the NHS mean that people living with HIV may access many different health services and organisations delivering health care. The 2007 standards have therefore been reviewed and updated to ensure that they appropriately reflect the current health care needs of people with HIV and are relevant to all health services that may provide their care.

In this document we describe 12 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 reaches the appropriate standards. Clear care pathways into and through HIV services at local, regional and national levels will be needed to ensure that people living with HIV are able to access the care that they need. Many people with

HIV have particularly significant social care needs that will impact on clinical care and compromise well-being. This means that an emphasis on integrated and collaborative care is essential if best outcomes are to be realised.

Scope of standards

We have developed standards of care for people living with HIV from acquisition of infection to end of life. Crucially, we include in this document people with HIV who are as yet unaware of their HIV infection, as they are at significant risk of inferior health outcomes and inadvertent onward transmission. Diagnostic testing for HIV is the key entry point for care, treatment and prevention services and is our starting point.

As the health and social care landscape evolves, care for people living with HIV will be delivered by a range of service providers, some more and some less HIV specific and experienced. 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.

The standards incorporate the appropriate care and services that people with HIV should be able to access to enable physical, psychological, emotional and social well-being and facilitate self-management, all of which combine to enhance quality of life and promote best health outcomes.

To ensure that services providing care for people living with HIV are relevant, appropriate and accessible, the standards include mechanisms for user engagement in service design and delivery.

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

These standards are not intended as an exhaustive list. Rather they 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 with HIV.

■ Aims of the standards

The aim is to define a minimum standard of care that a person with HIV should expect to receive. It is intended that implementation of these standards will help those living with HIV to achieve similar health outcomes to the general population.

These standards aim to inform:

- 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 care for people living with HIV
- People living with HIV about the expected standards of their HIV-related health care

This set of standards has been written in the knowledge of the existing Scottish HIV standards (2011) and the Psychological Standards for adults living with HIV (2011), and aims to complement these two publications.

■ Development of the standards

(for additional details see [Appendix 4](#))

Input from a wide range of stakeholders has been sought to ensure that the standards incorporate the key aspects of 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 with HIV might need, the document seeks to set out those areas of care that are fundamental to high-quality outcomes and that will facilitate delivery of the NHS Outcomes and Public Health Outcomes Frameworks (2012).

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

- Scoping and defining the key aspects of health care provision required to meet the needs of people living with HIV on which to formulate the standards statements. Two national workshops were held to help define the remit and the standard statements. Input was solicited from the attendees at the BHIVA national conference in April 2012. All BHIVA members were contacted to request input and feedback on the provisional standards statements.
- Drafting the quality statements, rationale, and the appropriate outcome measures for each standard. Working groups (led by a nationally recognised expert in the topic area, nominated by the chairs of the advisory panel) were tasked with drafting the appropriate content for each standard statement.
- Consulting widely across all relevant stakeholders for feedback and comments on the standards. The BHIVA Audit and Standards Subcommittee participated in the design of the auditable outcome measures. A web consultation process was undertaken during the autumn of 2012, and the standards further amended in the light of feedback received.

■ 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 Framework 2012/3 and the NHS QIPP agenda

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 and are in keeping with the ambitions of the QIPP agenda whilst sustaining high-quality care (see Appendix 2).

■ 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 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 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 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. Working out the ways in which people with HIV use the various elements of health care is a further resource for service planning and commissioning to ensure the best health outcomes for people with HIV.

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

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 in turn is an important factor in minimising clinical risk. 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 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 comorbidities expands across all sectors of the health economy the NHS number is already known for many people 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 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 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 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 number in HIV care with the aim of developing clear guidance to help both staff and patients understand the issues involved.

■ Language and terminology

The terminology used throughout this document is consistent with UNAIDS (2011) recommendations. Careful use of appropriate language, using terms that are clear and unambiguous, that put people first and that avoid perpetuating unhelpful stereotypes, is an important element of high-quality care.

References: 1–14

“ UK data from a wide range of health care settings has demonstrated that HIV testing is acceptable to patients, deliverable and saves lives. ”



■ Standard 1:

HIV 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

Approximately 25% 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; in 2010 50% of people who were newly diagnosed HIV positive were diagnosed late. Survival following HIV-associated opportunistic disease is associated with avoidable, potentially lifelong, morbidity. UK data from a wide range of health care settings has demonstrated that HIV testing is acceptable to patients, deliverable and saves lives.

Prompt HIV diagnosis affords opportunities to reduce transmission of HIV to other people.

For those who test HIV negative the repertoire of interventions to avoid infection

is increasing. Recognising primary HIV infection is important. This is a stage of high viraemia and hence infectiousness. Assays used must be appropriate to capture all stages of HIV infection. There are significant personal and social consequences of an HIV-positive diagnosis which must be recognised in any setting where HIV diagnostic testing is being carried out. Arrangements must be in place for appropriate onward treatment, care and support as required.

■ Quality statements

- We recommend that a routine offer of HIV diagnostic 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
- People presenting to clinical services where HIV may be an explanation for their condition should be recommended to have an HIV test.
- In areas where the prevalence of diagnosed HIV infection is 2:1000 or greater, all men and women admitted for secondary general medical care 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 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, 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 services funded for testing appropriate for their needs.

- 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.
- The use of diagnostic HIV assays which can simultaneously identify both antibodies to HIV and HIV p24 antigen (fourth-generation assays) is recommended to increase the opportunity to diagnose primary HIV infection.
- The time between performing an HIV diagnostic 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.

■ Measurable and auditable outcomes

- All HIV services should undertake a review of all patients presenting to care with advanced immunosuppression (CD4 count <200 cells/mm³ or AIDS diagnosis), with 'look back' of previous engagement with health care services. A summary 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.
- 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.
- 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.
- 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.

- 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.
- Proportion of services using the required HIV assays with a process for quality control.
- Proportion of individuals diagnosed late (CD4 count <350 cells/mm³) or very late (CD4 count <200 cells/mm³ or AIDS).
- Time between undertaking HIV testing and results being available and/or shared with the patient.

References: 5, 6, 15–18



■ Standard 2:

Access to, and retention in, HIV treatment and 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 must 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 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.

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).

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 7).

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 must 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. 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.

People may become disengaged from specialist HIV care for a variety of reasons, resulting from both patient- and service-related issues. People with mental health comorbidities and people who use drugs may be at particular risk. Unmet financial and social care needs are common in people with HIV and may have a deleterious impact on retention in care. 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 must be in place for seamless transition 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.

“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.”

■ Quality statements

Access

- All services that offer diagnostic testing for HIV must 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) must 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 and peer support.
- People who have a new diagnosis of HIV should receive/have access to emotional support/information 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, 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 must have mechanisms to identify people with HIV, registered with their service, who become disengaged from care.
- Clinical HIV services must have mechanisms in place to follow up people with HIV who miss appointments, monitoring tests or run low on supplies of medication.
- 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 must have defined pathways for the safe transition 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.
- 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.

- The proportion of people with known HIV infection 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 – 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).
- 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).

References: 1, 9, 19–23



■ Standard 3:

Provision of outpatient treatment and care for HIV, and access to care for complex comorbidity

.....

People with HIV attending an outpatient HIV service should have their HIV infection monitored and treated safely in accordance with national guidance, and be able to access a comprehensive range of specialist comorbidity services as required.

.....

■ Rationale

Monitoring and treatment for people with HIV infection needs to be in accordance with current national guidelines to maximise health and life expectancy and minimise morbidity and mortality. The combination of an ageing HIV cohort, longer duration of HIV infection and long-term antiretroviral therapy for HIV has resulted in a shift in HIV-associated pathology from ill-health associated with severe immunosuppression to non-AIDS comorbidities such as neurological, heart, liver and renal disease, and cancers. All HIV services have a key role to play in screening and monitoring people

for complications associated with HIV infection. However, not every HIV service will be in a position to deliver all aspects of complex HIV-related care. It is essential for clinical safety and service sustainability that clear pathways are established with local or regional specialist services to ensure that people with HIV have equity of access to appropriate specialist care whilst utilising available resources effectively.

There are aspects of care that all HIV services should provide. People living with HIV have the right to expect that their care is provided in a safe environment and that everyone is treated with dignity and respect without fear of discrimination.

All HIV services should have access to essential investigations that are routinely used in the care of people living with HIV, including CD4 lymphocyte counts, HIV viral load measurement and HIV genotype analysis, and should expect to receive results within 2 weeks of specimen collection.

Primary care has an important role in the long-term management of HIV. Indeed, due to the increase in non-AIDS comorbidity and the complexity of HIV drug–drug interactions, lack of communication with GPs has been shown to be an important patient safety concern. Establishment of clear protocols and pathways for care between both primary and secondary care is essential for safe delivery of care, and regular communication is strongly recommended unless the patient specifically refuses consent.

■ Quality statements

- People with HIV attending specialist HIV outpatient services should be in receipt of care and treatment that is in line with that defined by nationally recognised guidelines for the treatment of HIV infection and the complications of HIV infection and its therapy.
- People with HIV should be in receipt of care in an appropriate and designated waiting area, preferably dedicated, with privacy in consulting rooms, and with easy access to multidisciplinary support services – in particular: phlebotomy, specialist adherence/pharmacy advice, dispensing services, counselling, and welfare and advocacy support.
- People with HIV should have access to appropriate sexual health screening, treatment and advice (see Standard 7), as well as reproductive health services (see Standard 8).
- All services should have access to essential diagnostic investigations for the routine management of HIV and the complications of HIV therapy.

- All persons living with HIV should have access to emotional, psychosocial, and welfare advice and support (see Standard 6).
- People with HIV should have access to services to manage comorbidities safely, in collaboration with the appropriate non-HIV specialist team. The management of common comorbidities may be provided within the specialist HIV unit; otherwise clear pathways must be developed with regional services for people with complex and/or less-common comorbidities.
- 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.
- The management of everyone who has HIV with >2-class resistance/drug intolerance or a comorbidity that significantly impacts on antiretroviral choice should be discussed with specialist colleagues as part of a real or virtual clinic.
- All HIV services must have a pathway in place so that patients have 24/7 access to emergency treatment and advice.

■ Measurable and auditable outcomes

Preventing people dying prematurely

- Proportion of new patients who start therapy when indicated with a CD4 count of <350 cells/mm³ while not already being on therapy (numerator: patients not previously on therapy in denominator who have either started therapy or had a further CD4 count measurement >350 within 3 months of the index measurement; denominator: people who have a new CD4 measurement under 350 cells/mm³ [index measurement] within a defined time frame [e.g. 1 year]).
- Proportion of patients who are on ART if indicated by CD4 count and whose HIV is appropriately suppressed if on ART (numerator: those in denominator who meet any of the following criteria: [are not on therapy AND whose most recent CD4 count was >350 cells/mm³ in the last 6 months or was >450 cells/mm³ within the past 9 months] OR [are on therapy AND with VL <50 copies/mL within the past 6 months] OR [are on therapy but have been on therapy for less than 6 months]; denominator: whole cohort of patients under active follow-up).

- Number of patients whose viral load is <50 copies/mL and are still on therapy after 1 year (numerator: count of patients in denominator who are on therapy with viral load <50 copies/mL 1 year after initiating therapy; denominator: count of patients initiating therapy more than 12 months ago and less than 24 months ago).
- Proportion of patients who are alive within 1 year of diagnosis stratified by CD4 count at diagnosis (<350, 350–499, 500+) (numerator: number of newly diagnosed patients within CD4 strata who are alive within 1 year of accessing care; denominator: total number of newly diagnosed patients within CD4 strata).

Monitoring according to national guidelines

- Patients having a documented 10-year cardiovascular disease (CVD) risk calculated within 1 year of first presentation and within the last 3 years (target: 70% each).
- Patients with a smoking history documented in the last 2 years (target: 95%) and blood pressure (BP) recorded in the last year (target: 95%).
- Patients with urinalysis and/or urine protein/creatinine ratio performed in the last year (target: 90%).
- Patients with hepatitis A, B and C screening on diagnosis or first clinic appointment (target: 95%).
- Patients with a genotypic resistance test performed within 3 months of first diagnosis (or with a stored sample available for later testing) (target: 95%) (numerator: as per statement; denominator: total number of patients seen).
- 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, preferably dedicated, accommodating a layout and design that ensures patient confidentiality and privacy, supporting consultation and treatment rooms, patient waiting area, and with easy access to multidisciplinary support services – in particular:

phlebotomy, specialist adherence/pharmacy advice, dispensing services, counselling, and welfare and advocacy support.

- Survey of patient experience in the preceding 3 years (target: 95%).
- Ready access to defined support services within or close to the HIV service (sexual health advisor, counsellor, adherence specialist, pharmacy, phlebotomy).

Patient safety

- Evidence of recording of clinical incidents and complaints and their investigation (target: 95%).
- Evidence of a care pathway to demonstrate that all patients who have detectable HIV viraemia and two-class or greater and/or HIV multi-drug resistance 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 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 should be available to demonstrate that this is an actively used pathway, and should include an audit of HIV/HRG codes of local inpatient units.
- Confirmation from inpatient unit that referrals are received from HIV services.
- 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.
- At least annual communication with GPs about the care of people with HIV who are registered with and have shared the diagnosis of HIV with a GP (numerator: number of patients who have evidence of letter being sent to GP either less than 12 months since consenting OR less than 12 months since the last letter; denominator: number of patients who have agreed to GP letters being sent more than a year previously who have been on caseload for at least a year) (target: 95%).
- Evidence that the patient has been offered a copy of the clinic letter (target: 100%) and that this was dispatched where patient consent was given (target: 100%).

- Evidence that each patient has a nominated consultant for their HIV care (numerator: patients' case notes/equivalent records with documentation of nominated consultant; denominator: number of patients) (target: 95%).
- Evidence that there is provision of consultant advice and clinical supervision during routine outpatient working hours (target: 100%).

References: 19–21, 24



■ Standard 4:

Safe ARV prescribing: Effective medicines management

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. The pharmacokinetics and pharmacodynamics of these agents and their interactions is complex, and drug regimens must be tailored to meet the particular requirements of individual patients. Currently treatment for HIV is lifelong.

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, whilst 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-resistant strains of HIV. Prescribing of ARVs must 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 40% 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 such errors and promote good prescribing. Robust engagement with primary care to minimise potential drug interactions is an essential aspect of good prescribing practice.

Recommendations for effective medicines management have been highlighted recently in a King's Fund report and are incorporated into our quality statements below.

Antiretroviral drugs 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. The development of drug resistance and toxicity through inappropriate HIV prescribing would further increase costs.

■ Quality statements

- ARVs should only be prescribed by an appropriately qualified practitioner (see Standard 11).
- Clinicians prescribing ARVs must maintain antiretroviral prescribing competencies on a continuing basis with evidence of HIV-specific CPD, and evidence of clinical Programmed Activities 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 (see Standard 10).
- Adherence to antiretroviral therapy should be assessed at each clinic visit, and all HIV services should follow a written protocol for supporting adherence to ARVs.

- 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 failure or suspected low adherence occurs.
- There should be evidence of self-reported adherence at each clinician visit. Any patient reporting missed medication or viral load rebound should receive adherence support.
- Information relating to all treatments prescribed should be recorded in the patient's clinical records alongside other medical conditions, and be identified by the patient's name and date of birth.
- Drug histories should be undertaken at each clinic visit and should include details of all prescribed medication from primary care and HIV service, over-the-counter medication, herbal medication and recreational drugs. This information should be documented in the clinical record.
- A complete medication review should be undertaken at least annually by the specialist team, taking into consideration adherence, any difficulties with medication and drug–drug interactions. This should be documented in the clinical record.
- All prescribers of ARVs should be able to readily access and regularly use IT and decision-support tools to support best prescribing practice, and to help reduce medication errors.
- Antiretroviral prescriptions should be clinically verified by a competent 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 that provide educational information and outreach services to support antiretroviral therapy prescribing for difficult-to-reach patients in the local community.
- HIV services and patient representatives should collaborate 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.

■ Measurable and auditable outcomes

- Evidence of clinical appraisal of HIV therapy prescribers, which records participation in relevant CPD activities on HIV therapy.
- Proportion of all patients who have a documented medication review in the past 12 months.
- The HIV service should be able to demonstrate that patients with virological rebound are rapidly recognised, discussed in an MDT, and have access to specialist treatment and adherence support.
- Proportion of patients prescribed first-line therapy who have not developed evidence of new drug resistance 1 year later (target: >98%).
- Adherence documented within the first 3 months of starting ART and at least annually thereafter (target: 95%, both).
- Patients with HIV viral load assessed within 6 weeks of commencing ART (target: 95%).
- Patients on ART with HIV viral load measured within the last 6 months (target: 95%).
- People with HIV who are new to treatment prescribed ART according to BHIVA treatment guidelines (target: 75%).
- The HIV service should be able to provide evidence that involvement in treatment decisions is routinely offered to all patients, and that such involvement is widespread across all persons with HIV under active follow-up. This includes not only discussions around treatment choices, but also reporting of adverse effects of their treatment (see Standard 10).

References: 20, 25–33



■ Standard 5:

Inpatient care for people living with HIV

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

HIV-positive people presenting with complications of HIV infection are often critically ill with life-threatening conditions and require complex care. Care for these patients should be provided by an HIV specialist consultant-led multidisciplinary team, frequently in collaboration with other medical specialties. A national audit of deaths in HIV-positive adults in 2004/05 found that 56.3% were attributable directly to HIV disease, largely AIDS-defining conditions, with late presentation and diagnosis being

the significant contributing factors to the mortality of otherwise treatable AIDS-defining conditions. If appropriately managed, people presenting with severe HIV-related pathology should expect a good long-term prognosis. Best clinical practice for the management and treatment of HIV-associated opportunistic infections and cancers is outlined in national and international guidelines.

The spectrum of illness seen in HIV-positive patients has changed over the last decade. The use of effective antiretroviral therapy in people known to have HIV infection has led to fewer people requiring inpatient care for the immunosuppressed complications of HIV. For the 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 advice and care. Network arrangements will ensure that HIV services maximise critical mass in order to provide adequate experience to adhere to 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 an increase in other end-organ pathologies. 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, end-organ liver and renal disease.

Providers of outpatient HIV care must have documented pathways to appropriate inpatient services. It is accepted that not all HIV-positive 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 must, however, be supported by immediate and continued engagement with specialist HIV expertise and advice, allowing for early transfer should complexity of care escalate. Specialist HIV inpatient services must also be in a position to provide support and advice to acute medical services when a patient is too 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 the treatment of HIV infection and complications of HIV disease and therapy.

“ Providers of outpatient HIV care must have documented pathways to appropriate inpatient services. ”

- 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 who are HIV positive and require inpatient admission should experience high standards of confidentiality, privacy and dignity in line with the law, GMC guidance 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 who are HIV positive and who require admission to hospital should experience effective 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 HIV positive and who are admitted to hospital should be protected appropriately from nosocomial and cross-infection. Service arrangements should be in place to reduce and avoid risk of nosocomial and cross-infection and to ensure immediate access to isolation facilities.

Care arrangements of HIV inpatient units

- Arrangements for care in specialist HIV inpatient services must ensure there is:
 - Provision of 24-hour access for acute care
 - Co-location with HDU and ITU services with appropriate escalation of care to HDU and ITU when indicated
 - 24-hour availability of pharmacy services and access to specialist HIV pharmacist advice
 - An HIV specialist consultant physician-led multidisciplinary team
 - A nursing team with HIV specialist nursing skills and expertise
 - 24-hour availability of HIV specialist inpatient consultant advice and expertise (locally or via a network)
 - Access to diagnostic laboratory services as required
 - Access to other medical and surgical specialty advice and services when required
 - Access to psychosocial and welfare advice and support
 - 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 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 seen in HIV outpatient services within 1 month (target: 95%).

- Evidence of review of all deaths of patients admitted to an HIV specialist 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 and complaints and their investigation.

References: 1, 9, 20, 21, 24, 34–38



■ Standard 6:

Psychological care

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

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This section draws extensively on the Standards for psychological support for adults living with HIV (2011) and the two should be read in conjunction.

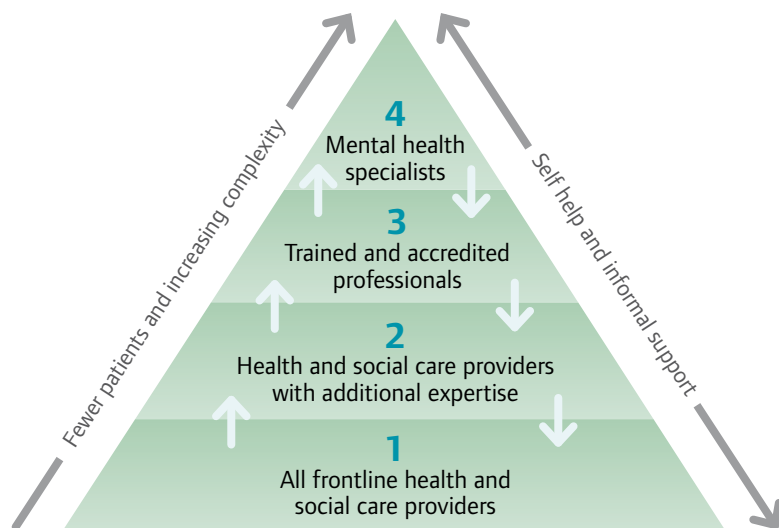
■ Rationale

People living with HIV experience significantly higher rates of depression and other psychological problems than the general population. This has a major impact on quality of life, complicates clinical care, compromises physical health and heightens the risks of onward HIV transmission, making promotion of mental health and well-being for people with HIV of critical importance. Appropriate and timely psychological support is an essential component of good clinical care; people with HIV should have access to services that assess emotional and psychological well-being, detect potential psychological problems and plan appropriate interventions in terms of stepped-care interventions that are delivered by appropriately qualified providers.

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Identification of psychological problems and cognitive impairment through screening is valuable. It should be repeated annually and following events known to trigger or exacerbate psychological distress or cognitive difficulties, such as significant changes in physical health or disease progression, starting antiretroviral therapy, difficulties with adherence and returning to clinical care after being lost to follow-up. Other triggers include significant life events such as a difficult relationship break-up, experiencing stigma or violence, losing benefits or a sudden death of a loved one. Screening can range from brief questions (e.g. “Have you noticed any problems with your mood or memory over the past year?”) and move to more complex tools, such as validated questionnaires and brief cognitive tests, depending on the response to initial screening questions. For someone who is not experiencing any difficulties, screening might be limited to one or two questions. For those where there are concerns, screening can be escalated, with appropriate onward referral.

The stepped-care approach should be used to enable access to the appropriate psychological support services and cognitive rehabilitation needed by each individual (see figure below). This provides a framework for comprehensive assessment and provision of psychological support to meet the range of needs of people with HIV. While the particular services available locally may determine how such support is provided and by whom, all aspects of assessment and support described in the model should be available regardless of geographic location.



Clear pathways should be defined between those services providing HIV clinical treatment and those offering psychological support. Psychological support may need to be delivered through a network of providers with a variety of expertise and should include access, when necessary, to local mental health services, including psychiatric and community support, and be linked to social services and services for managing the functional impact of psychological difficulties. Services should be planned to provide seamless integration across the various levels of psychological support, including transitions between services for people of all ages living with HIV.

“ People living with HIV experience significantly higher rates of depression and other psychological problems. ”

Psychological support services should be high-quality, accessible, needs-based and strategically planned with clearly defined and accountable leadership and management arrangements. Clinical leadership should be provided by practitioners who have level 4 psychological support skills with particular expertise in HIV. Clinical leads should be part of the multidisciplinary team providing HIV care, communicate effectively and collaborate with the professional leads of other services providing psychological support for people living with HIV (e.g. social care and voluntary sector), and work closely with commissioners.

Required competencies should be defined across the spectrum of four levels of psychological support and cognitive rehabilitation. Practitioners need to demonstrate their competence on an ongoing basis. Services should support the maintenance of such competencies through training, continuous professional development and supervision. In addition to generic competencies required by practitioners for their particular role and professional qualification, all practitioners should be able to display a minimum set of competencies demonstrating their awareness and understanding of HIV and its impact on those living with the disease. They should possess an awareness of the diversity of needs that people living with HIV may have.

See Standards for psychological support for adults living with HIV for additional information on the identification of psychological support needs, the stepped-care model, and the required competencies for practitioners delivering psychological support.

■ Quality statements

- People living with HIV should have access to regular screening to identify their psychological support needs.
- When concerns are raised in screening, people living with HIV should have access to more comprehensive psychological and cognitive assessments, interventions and rehabilitation by suitably competent professionals.
- People living with HIV should be screened for the presence of symptoms of depression, anxiety, drug and alcohol misuse, acute stress disorder, risk of self-harm and cognitive difficulties within the first 3 months of receiving an HIV diagnosis.
- Such screening should be repeated regularly on an annual basis, and following events known to trigger or exacerbate psychological distress or cognitive difficulties.
- Screening may vary from documented responses to specific screening questions, to screening measures and cognitive tests, all of which should be empirically validated for use in HIV or with other chronic health conditions.

- Referral pathways must be in place for further assessment by a suitably competent professional should screening indicate potential support needs.
- People living with HIV should have access to a range of psychological support services appropriate to their needs.
- People living with HIV should have access to a range of cognitive rehabilitation services appropriate to their needs.
- Psychological support and cognitive rehabilitation services should be organised and provided in line with the stepped-care model as endorsed in the Standards for psychological support. Support services should be effectively coordinated within a managed clinical framework.
- Psychological support and cognitive rehabilitation should be provided by practitioners who are appropriately trained and have demonstrated required competencies.

■ Measurable and auditable outcomes

- Among attending patients, the proportion who receive some form of screening for psychological and cognitive difficulties at least once a year.
- Where psychological support needs have been identified, the proportion of patients who are referred onward for appropriate intervention and/or cognitive rehabilitation.
- Evidence of inclusion of psychological support at all four levels with agreed referral pathways.
- Evidence that patients are satisfied with:
 - The response of services to their psychological support needs
 - The coordination of the delivery of their psychological support
 - The impact of psychological support on their quality of life and well-being
- Clinical and management teams of each service which include an identified clinical lead for psychological support.

- The proportion of practitioners within a service delivering psychological support who have successfully completed competency-based training according to their scope of practice and the proportion of practitioners who have fulfilled relevant CPD requirements.

References: 9, 39–52



■ Standard 7:

Sexual health and identification of contacts at risk of infection

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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/contact 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 HIV testing with appropriate consideration of confidentiality and safety.

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■ Rationale

Good sexual health is part of good overall health. The impact of living with HIV, a potentially stigmatising sexually transmissible infection, must 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 in the context of HIV therapy, issues around HIV disclosure and fear of criminalisation.

Sexually transmitted infections are more common in people living with HIV. Men with HIV who have sex with other men bear a disproportionately heavy burden of STIs. HIV-positive people are at a greater risk of complications from STIs such as hepatitis B and C, human papilloma virus (HPV), herpes simplex virus (HSV) and syphilis. Prompt identification and treatment is important as concomitant infection increases the risks of HIV transmission/acquisition.

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 must not be compromised by anxieties about any legal issues relating to sexual transmission of HIV infection.

“ Sexual health assessment needs to be a regular part of health monitoring for people with HIV. ”

Partner notification for HIV and/or other STIs is an important public health strategy, facilitating early diagnosis among known sexual partners. Further HIV infections can be minimised by ensuring sexual partners are aware of the presence of HIV within the relationship, and are able to access risk reduction counselling and antiretroviral medication, either as prophylaxis if negative (in the form of PEPSE), or treatment if HIV positive. People living with HIV must 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 HIV-positive parents, irrespective of their age and health status, has been highlighted by *Don't Forget the Children* (<http://www.bhiva.org/documents/Guidelines/Dont%20Forget%20the%20Children/DFTC.pdf>), which provides relevant guidance. 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.

■ Quality statements

Sexual health

- Sexual health assessment needs to be a regular part of health monitoring for people with HIV.
- All those living with HIV should have easy access to investigation, diagnosis and treatment for STIs, in line with national guidance. Referral pathways to GUM should be in place in all HIV services.
- 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 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.

- People living with HIV must be able to access preventative vaccines for hepatitis B and other sexually transmitted infections 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.

Contacts at risk of HIV infection

- The HIV status of all children born to people living with HIV in the UK 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 HIV positive 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 whenever there are new partners whose HIV infection status is unknown.
- 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, and outcomes documented in the clinical record.
- 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 post-exposure prophylaxis.
- People living with HIV should be offered access to 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.
- 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 in the clinical record that all persons identified to be susceptible to hepatitis B infection at initial HIV diagnosis are offered a course of vaccination.
- 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 (target: 90% of patients).
- 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 (target: 90% of patients).
- Documented PN outcomes or a progress update at 12 weeks after the start of the process (target: 90% of patients).
- 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 HIV-positive patients).
- 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.
- Evidence of a patient experience survey to assess satisfaction regarding discussion around HIV testing of their children.

References: 53–62



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■ Standard 8:

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 must be able to access appropriate health care services for a safe pregnancy and childbirth which provide the best chance of having a healthy infant.

■ 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 unprotected sexual activity or vertical transmission, together with concerns about parental health and longevity, complicate the situation for people with HIV. Regulation of fertility services in relation to HIV has made access more difficult for people who are HIV positive than people who are HIV negative.

People with HIV may wish to plan pregnancies, to limit their families, or to avoid pregnancy altogether, and therefore require advice on and access to a range of contraceptive methods. Hormonal contraception requires particular care in prescribing to avoid significant interactions with antiretroviral drugs.

An increasing number of people with HIV are requesting advice around safe conception. Couples who are either seroconcordant (both HIV-positive) or serodifferent (one partner HIV positive and one partner HIV negative) require different clinical management approaches. Alternative methods of conception such as self-insemination can enable women who are HIV positive to become pregnant without risk of acquisition of HIV by a male partner who is HIV negative. Likewise, methods such as timed unprotected sexual intercourse for men with HIV who are on successful antiretroviral therapy can be employed to reduce the risk of acquisition of HIV by a female partner who is HIV negative. 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-1, coupled with appropriate management for women with HIV during pregnancy and delivery, and women and their infants postnatally, results in rates of vertical transmission in the UK that are between 0.1% and 1%. The provision of appropriate care during and after pregnancy, including the use of antiretroviral therapy (ART) and obstetric intervention, continues to evolve.

■ Quality statements

- The reproductive health of HIV-positive people should be addressed by HIV services, with reproductive counselling and support available within HIV services.
- All women who are HIV positive should have access to accurate information about contraceptive choices, including specialist advice on safe options 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 if appropriate.

- People 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 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 referral to 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
 - Within hours of the initial result: for a pregnant woman newly diagnosed HIV positive, who has HIV-related symptoms, or is in labour or is within days of her expected delivery date
- The management of pregnancy, childbirth and the immediate postnatal period for women 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.
- Provision of antiretroviral drugs in pregnancy is within the scope of an outpatient HIV unit, but birth plans and plans for paediatric care must be managed in collaboration with obstetric services and local/regional paediatric HIV teams.

- All mothers known to be HIV positive 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.

■ Measurable and auditable outcomes

- Proportion of people living with HIV with documented discussion of reproductive choice and contraception during defined period (numerator: number of adults/adolescents with documented discussion during defined period; denominator: total number of adults/adolescents attending HIV service during defined period).
- HIV services should be able to demonstrate that they have care pathways for people who are HIV positive with contraceptive, conception and fertility 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 must 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 to assess satisfaction regarding discussion around reproductive health and conception options.

References: 3, 38, 54, 64, 65



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■ Standard 9:

Self-management

People living with HIV should be enabled to maximise self-management of their physical and mental health, their social and economic well-being, and to optimise peer-support opportunities.

■ 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 to gain confidence, skills and knowledge to manage their own health, with resulting improvements in quality of life and independence.

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 amongst 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 issues and symptoms which it presents. Effective self-management allows people with HIV to make the many daily decisions that improve their health-related behaviours and outcomes.

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. 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 four interconnected major areas:

- Physical health and well-being, including both HIV-specific and general health matters
- Mental health and well-being
- 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 frequently best placed to know and understand their own needs.
- It allows people to take greater personal responsibility for their own health and well-being.
- Professional resources can be focused where they are most needed.

Services that provide care for people 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 interventions 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. Depending on the needs identified, referral

to and interventions from occupational therapists, physiotherapists and speech and language therapists can optimise functionality which will facilitate many other aspects of self-management. Referral to and interventions from dietitians can facilitate lifestyle behaviour changes that will either prevent or reduce the risk of long-term consequences associated with over- or under-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 web-based programmes. HIV services should develop delivery models using information technology that supports people in achieving the goal of greater self-management. It is important to ensure that there is 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 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.
- Provision of support and information on maximisation of entitlement to health services and support.
- Provision of support and information to enable people to optimise their entitlement and access to financial and housing support, and to optimise their ability to gain/regain employment.
- Self-management services including access to peer-support opportunities should be available in a choice of modalities, and should be accessible both via HIV specialist clinical services and by direct access.
- HIV services should have referral arrangements in place to enable people living with HIV to access services delivered by HIV support services either locally or by remote access (e.g. online or via telephone).
- Services should be delivered by providers with appropriate expertise and competencies. Wherever appropriate and relevant, providers should have the requisite professional qualifications and be appropriately accredited.

- HIV services should seek to optimise 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).
- HIV services to be able to demonstrate mechanisms in place to facilitate referral for people living with HIV to self-management services.

References: 9, 37, 38, 63, 66, 67



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■ Standard 10:

Participation of people with HIV in their care

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People living with HIV should have opportunities to be actively involved in decisions about their health care. People who use HIV clinical services should have opportunities to be involved in the design, planning and delivery of these services.

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■ 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.

Professional regulatory bodies expect people receiving care and health practitioners to make informed decisions about treatment and care together. 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

set out similar requirements. GMC guidance for shared decision-making suggests that clinicians:

- Listen to patients and respect their views about their health.
- Discuss with patients what their diagnosis, prognosis, treatment and care involve.
- Share with patients the information they want or need in order to make decisions.
- Maximise patients' opportunities and ability to make decisions for themselves.
- Respect patients' decisions.

HIV is a life-long 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.

British HIV Association guidelines recommend that people with HIV be given opportunities to be involved in making decisions about their ART treatment. Trust and good communication between the person receiving care and the health care practitioner are associated with better adherence and outcomes. A range of information resources and peer-support services, including printed and web-based information, telephone advice lines, treatment advocates and peer-support groups are an important complement to clinical services and are helpful in addressing the following factors that may impact on achieving good outcomes:

- 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, such as disclosure
- Confidence in the ability to adhere to ART and the importance of adherence

- Psychological or cognitive issues that could impact on adherence, for example, depression and drug or alcohol use
- Socio-economic or cultural factors that could impact on adherence, for example income, housing, faith or domestic violence

Involving people with HIV in their health care supports long-term, chronic condition self-management (see Standard 9). Shared decision-making and self-management can be supported by high-quality, accessible information 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 planning 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 the patient in contributing to service planning. Such support can be provided by community organisations and networks.

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

■ Quality statements

Individual decisions about treatment and care

- 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, 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
- 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 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 both clinicians and people with HIV, in particular for those whose background circumstances may militate against 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 to be involved in service planning and review of delivery. 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 fruitful engagement and consultation with service users.

■ 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).

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 in service design and performance review.

References: 20, 37, 38, 68–71



■ Standard 11:

Competencies

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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.

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■ 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 HIV positive is complex, requiring management of issues ranging from transmission, immunosuppression, infectious and non-infectious complications, coinfections, comorbidities, antiretroviral treatment, and 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) and that the members of the team have the appropriate competencies to undertake this care safely and effectively. It is important that care is provided within a suitable and recognised management structure for appropriate accountability and essential that continued teaching, training and sharing of best practice is in place.

At some times and in some places not all the clinical services required by a person with HIV will be available within the local team. It is important that network arrangements to deliver such services are in place and that timely referral is made to practitioners with the appropriate knowledge and skills working in institutions with appropriate equipment and infrastructure to provide these specialist services (see Standard 5).

■ Quality statements

- Provision of HIV care should be a recognised activity at the trust/organisational level. There must be clear lines of accountability through appropriate clinical directorate(s) right up to board level.
- People who are HIV positive should experience care that is delivered to the highest standards of confidentiality, privacy and dignity, in line with GMC guidance and national standards.
- HIV remains a stigmatising condition that disproportionately affects already vulnerable people, and all staff at all levels in any HIV service must have appropriate training and induction organised by the service in HIV awareness.
- All health care professionals engaged with provision of specialist HIV services are required not only to maintain their competencies, but should also be supported to disseminate their expertise through teaching, training and sharing of best practice.

Medical team

- The HIV-related knowledge and skills required for GU medicine specialist trainees to complete training are outlined in the syllabus of the GU medicine curriculum (Learning objectives 21–38 www.jrcptb.org.uk). For infectious disease specialists the 2010 curriculum for infectious diseases (± tropical medicine) gives details of 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 compulsory for specialist trainees in genitourinary medicine enrolled on the 2010 curriculum (or later). The syllabus for the exam is updated regularly. 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 Specialty Certificate Examination (SCE), which includes assessment of HIV medicine. The details of this exam, including the syllabus and blueprint, can be viewed at www.mrcpuk.org/SiteCollectionDocuments/SCE_ID_Blueprint.pdf
- A majority of current consultants caring for patients with HIV do not at present hold the Dip HIV Med, but the examination syllabus can act as a useful resource for appraisal and re-validation. During appraisal (to be completed annually), HIV-specific continuing professional development (CPD) should be assessed and this should be further reviewed during 5-yearly re-validation. Personal development plans should include educational or training activities that relate directly to HIV care. Usually this will include attendance at a national or international meeting at least once every 2 years. For specialists undertaking inpatient care of people with HIV (see Standard 5), 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 include those organised by the RCP and BHIVA.
- For non-specialist doctors and trainees undertaking care it is essential that there is a named clinical supervisor who is a specialist in HIV medicine and that regular and appropriate clinical supervision takes place in addition to annual appraisal and 5-yearly re-validation.

Nursing team

- Specialist HIV nursing should be provided by registered nurses, with support from health support workers if appropriate. The knowledge and skills required for specialist HIV nursing care are outlined in the NHVNA National HIV Nursing Competencies (June 2007; currently under review). Registered nurses should demonstrate competence to the appropriate level in the four core areas of assessment of health and well-being, management of ART, health promotion and working in partnerships; and additionally where relevant the specialist competencies for outpatients, inpatients, research or paediatrics. 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 NHVNA competency framework.
- Nurses are required by the Nursing and Midwifery Council (NMC) to undertake and record 35 hours of learning activity relevant to their role over 3 years to retain their registration. Learning opportunities for specialist nurses are: NHVNA on-line training 9 hours CPD at level 2, and 1.5 hours at level 3 (www.hivinsight.co.uk), some HIV modules at diploma and degree level and local/national conferences and study days. Nurses working in advanced practice should undertake non-medical prescribing and preferably undertake master's-level education, although currently this is only locally determined by health trusts.

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. They should have current appropriate knowledge and skills and be appraised annually. They should complete at least nine mandatory CPD entries each year to 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. Specialist pharmacists who practise as non-medical prescribers will, in addition, fulfil the requirements of the National Prescribing Centre Competency Framework for Prescribers, under the supervision of an HIV consultant. They should have shared access to the patient care record and prescribe within their scope of practice.

Allied professionals

- The exact composition of the multidisciplinary team will depend on the size and location of the HIV service. Members of the team should work within the relevant management and governance structure of their organisation and work within the competencies for the applicable profession. Annual appraisal, including an assessment of HIV-related activities, should be undertaken by all professions irrespective of discipline.

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 (in publication). 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.

“ Ensuring patient safety and delivering care of the highest quality are fundamental responsibilities of health and social care providers. ”

Rehabilitation team

- Physiotherapists, occupational therapists and speech and language therapists should be registered with the Health and Care Professionals Council (HCPC) and in addition to the HCPC more specific competencies are outlined in the RHIVA Competencies (2012). Physiotherapists working in any setting should have advanced or senior-level skills in neurological, respiratory and musculoskeletal practice, whilst 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 a RHIVA study day or an on-line HIV rehabilitation module.

Competencies to prescribe ARVs

- Possession of the requisite competencies to prescribe ARVs has been more clearly defined for some prescribers than for others.
- For medical practitioners, specialist training in infectious diseases and genitourinary medicine requires demonstration of competence in prescribing, monitoring and supporting antiretroviral therapy. This may be gained in practice or delivered through basic and advanced specialist courses, and assessed in training and through successful acquisition of diplomas in GUM, HIV or infectious diseases. Engagement in specialist training, or specialty certification in genitourinary medicine, infectious diseases or general internal medicine can provide evidence of ARV-prescribing competency, which may be supported by a demonstrable HIV caseload and acceptable treatment outcomes. Nurses and pharmacists carrying out advanced practice roles such as nurse/pharmacist consultant, senior clinical practitioner or senior nurse/pharmacist manager may prescribe under the supervision of an HIV consultant within the scope of supplementary or independent non-medical prescribing according to local and national protocols (NPC Competency Frameworks, 2012; NHIVNA National HIV Nursing Competencies, 2007; and HIVPA & Specialist Curriculum Group Handbook for Specialist & Advanced Practice in HIV, 2009).

■ Measurable and auditable outcomes

- Consultant physicians: proportion having appraisal date within last 12 months; proportion with HIV-related topic in personal development plan, evidence of ongoing CPD in HIV, evidence in job plan of HIV-related activities appropriate to the clinical caseload. Proportion with job plan containing HIV practice revalidated by GMC.
- Non-specialist doctors: proportion with named HIV clinical supervisor; proportion having appraisal date within last 12 months; proportion with HIV-related topic in personal development plan (or could be changed to: provide evidence that all non-specialist doctors have a named HIV clinical supervisor).
- Nurses/pharmacists/allied health professionals: appraisal, documented HIV CPD, competency assessment.

- Trainees, all professions: named supervisor and evidence of supervision of HIV practice.
- All HIV services should provide evidence of involvement in the delivery of appropriate training/educational opportunities within and outside their own institution.

References: 9, 25, 26, 72–75



■ Standard 12:

Information for public health surveillance,
commissioning, audit and research

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Services delivering HIV care should actively provide data
to national surveillance programmes and national and local
audits, and for research purposes.

People with HIV should expect to be informed of opportunities
to take part in ethically approved research that is relevant to
their health and care.

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■ Rationale

Service providers routinely collect data relating to the care received by people living with 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; audit the quality of care received by patients; inform the commissioning of services and development of clinical guidelines; and drive clinical research.

Public health surveillance

Data collected locally are sent securely to the Health Protection Agency (HPA) and its successor 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, monitor access to HIV care and treatment, and to target prevention initiatives.

Local and national audits

Clinical audit is a key driver for improving the quality of care available for people with HIV by checking whether current best practice is being followed and to identify where improvements should be made if there are shortfalls in the delivery of care. Audits may be completed at the national, regional or local level.

Commissioning and provision of services

The commissioning of services is reliant upon timely and high-quality data collected at the provider level. These data are used to ensure that services are adequately funded and provide a high quality of care.

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.

Information governance

Confidentiality of the personal and clinical details of people with HIV is of paramount importance. Any data collection processes that involve people with HIV must deliver the appropriate level of confidentiality that is required by law, ethics and policy. At all levels, identifiable or potentially identifiable data must be held securely with access strictly restricted to trained data managers and clinical/epidemiological/research staff, and in compliance with information governance standards and the relevant legislation. For national surveillance data, this includes National Information Governance Board (NIGB) approval under section 251 of the NHS Act 2006 for the HPA to collect patient-identifiable information without consent; this will be directly transferred to

Public Health England. All staff within the HPA/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. Secondary analyses of these data may also be conducted for surveillance and research after patient identifiers have been removed.

NHS number

A person's NHS number is the key identifier for data linkage across NHS services and its use has the potential to facilitate accurate understanding of service use, planning service development, and joining up the various elements of care within the patient pathways and across providers. The use of the NHS number in HIV services would offer significant advantages for accurate data collection. The use of the NHS number can allow for pseudonymised linkage of HIV service data with other NHS services, enabling audit of, for example, inpatient admissions, primary care cardiovascular management, immunisations, cervical cytology etc.

■ Quality statements

- 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 must 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 must have clear mechanisms for ensuring data quality – ideally direct extraction from an electronic clinical record system, which is accurately maintained in real time.
- Providers of HIV services must actively participate in public health surveillance, national clinical audits and applicable research programmes.
- Public health surveillance data should be submitted electronically via a secure web portal within 6 weeks of the end of the reporting period. Inconsistencies in data must be corrected within 2 weeks of notification.
- All providers of NHS HIV care (which may increasingly include independent providers) should take part in relevant national and local audit and applicable research programmes. Where taking part in a research programme, data should be provided in a timely manner, as agreed with study investigators.
- 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

- Evidence from the Health Protection Agency (and its successor 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 6 weeks of the reporting period close
 - Complete (mandatory fields should be 90% complete) and consistent data
- Evidence from the Health Protection Agency/Public Health England or Health Protection Scotland that information has been used to:
 - Produce national public health outputs
 - Inform commissioning
 - Audit national standards

- Service providers should demonstrate:
 - They provide information for local audits
 - Evidence of completion of audit cycles relating to HIV in response to audit outcomes
- Evidence that all NHS HIV services are aware of HIV-relevant research within the NIHR research portfolio, are actively involved in such research, and that mechanisms are in place to alert patients to relevant research programmes.

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Appendix 1

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Appendix 2

■ The NHS Outcomes Framework

Linking the Standards of Care for People Living with HIV (2013) to the NHS Outcomes Framework (2012/3)

NHS Domain 1 Preventing people from dying prematurely

Late and very late diagnosis is a major cause of diminished life expectancy for people with HIV; avoiding late diagnosis by increasing the uptake of diagnostic testing for HIV is a critical intervention to address this and is discussed in Standard 1. Access to and retention in HIV specialist care (Standards 2 and 3), together with safe medicine administration (Standard 4) delivered by competent professionals (Standard 11), underpin increased survival for people with HIV. HIV-associated complications may be life-threatening and their management specialised and complex, requiring ready access to specialist inpatient facilities and advice (Standard 5). Addressing and improving poor mental health (including cognitive impairment) in people with HIV (Standard 6) is an important requirement for maximising the other areas of care. Ensuring high-quality reproductive health for people with HIV (Standard 8) reduces the risks of vertical transmission of HIV, preventing morbidity and mortality in the children of people with HIV. Undertaking a full review of all deaths in people with HIV (Standard 12) allows lessons to be learnt for future care. Preventing the onward transmission of HIV (Standard 8) is the best way to avoid HIV-related morbidity and mortality.

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

For people with HIV who are diagnosed in time (Standard 1), have access to and engage with specialist care (Standards 2 and 3), HIV can become a long-term chronic condition. Preventing the complications of HIV, and if/when they occur, initiating prompt appropriate management (Standards 3 and 5), minimises HIV-associated morbidity. Optimising psychological and emotional health (Standard 6) not only enhances quality of life but underpins many other aspects of a healthy and fulfilling life, including sexual relationships (Standard 7) and family life (Standard 8). Living well with HIV for the long term calls for strong self-management skills (Standard 9) and full participation in the decisions made about all aspects of treatment and care, service design and delivery (Standard 10). Long-term conditions require coordination and integration across providers and structures within health care (primary, secondary and tertiary) and social care (Standards 3 and 9). Monitoring outcomes through high-quality data from surveillance, audit and research (Standard 12) allows for ongoing development and improvements.

NHS Domain 3 Helping people recover from an episode of ill-health or injury

People with HIV experience a wide range of complications resulting from the direct effects of HIV, its treatment and an increasing range of associated comorbidities. Prompt diagnosis and access to appropriate specialist care and, where required, admission to HIV-specific inpatient facilities for complex treatment (Standard 5), assists recovery. Multidisciplinary team-working across a wide range of competent professionals (Standard 11), with the person with HIV at the centre (Standards 9 and 10), and supporting people through the psychological impact of serious illness (Standard 6), are crucial factors for regaining well-being. Helping people with HIV acquire self-management skills (Standard 9) and full engagement in all treatment and care decisions (Standard 10) allows people with HIV to prepare for, cope with and recover from the episodic complications they are likely to face.

NHS Domain 4 Ensuring people have a positive experience of care

The evaluation of patient experience is vital to delivering improvements in care. Evidence has previously shown that patients often experience poorer care at the points in their pathway between one organisation or team, and another, which makes this domain particularly important in the lives of people with HIV. These standards include a number of outcomes evaluating the experience of care in people with HIV in a number of settings where multidisciplinary working is essential in patient care (complex outpatient care, inpatient care, pregnancy) and in cases of poor emotional and psychological well-being (Standards 3, 5, 6 and 8).

Ensuring a positive experience of care for someone living with HIV is more than achieving good clinical endpoints. A positive patient experience in HIV requires good communication skills and allowing the patient to feel comfortable having informed discussions about issues which matter to them, such as living healthy sexual and reproductive lives (Standards 7 and 8), feeling safe and secure when attending for care (Standards 3 and 5), and feeling reassured that care is being provided by people competent to manage their condition (Standard 11).

People with HIV should be partners in care rather than passive recipients of it. Maximising patient involvement in service design will lead to continued service improvement (Standard 10).

To protect people with HIV from avoidable harm, it is essential to maximise opportunities to be aware of HIV infection before the immune system is significantly damaged (Standard 1). HIV-related stigma can present dangers for people with HIV which must be taken into account in HIV diagnosis, treatment and care. Treating and caring for people in a safe environment facilitates ongoing engagement with care (Standards 2, 3 and 5). Helping people with HIV discuss their condition with their partners and families in a way that keeps them safe and prevents breakdown of relationships (Standard 7) is a vital aspect of care. Fluent communication between HIV specialist care and other secondary and primary care teams will prevent harm to people with HIV (Standard 3 and 5). Medication management with high-quality prescribing, which involves effective communication between all prescribers (Standard 4), is vital in the avoidance of harm. Shared care for people with complex comorbidity is discussed in Standard 3. Ensuring inpatients receive appropriate care, whichever hospital they present to in the UK, is discussed in Standard 5.

All those who provide care to people with HIV must stay up-to-date and maintain their competencies to ensure that they are fit to practise safely. Standard 11 sets out the competencies of a range of HIV practitioners required to ensure the safety of patients and their environment, and to provide high-quality care that enhances the experience of people living with HIV.

People with HIV must be able to have complete confidence in the security of their clinical and personal data. Any information gathering, storing or sharing by HIV services must deliver the appropriate level of confidentiality that is required by law, ethics and policy (Standard 12).

The BHIVA Standards of Care for People Living with HIV have been produced using the NHS Outcomes Framework as a guide and drawing upon the QIPP agenda through the joint workshops with NHS Right Care. The points above are merely to highlight some of the many areas of convergence between these Standards and the NHS Outcomes Framework. They are not intended to be exhaustive.

Appendix 3

■ Glossary of terms and abbreviations

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

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

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

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

BHIVA British HIV Association. Information at www.bhiva.org

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

CD4 count: The number of CD4 T-helper lymphocytes in the blood. Someone without HIV infection normally has a count between 500 and 1200 cells/mm³.

CHIVA: Children's HIV Association. Information at www.chiva.org

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

Continuing Professional Development/CPD:	An ongoing commitment to learning in various forms, which maintains knowledge and skills, and which enhances professional standards of work. This is an obligatory component of most professions.
Designated:	A specified place or person that is identified for a certain purpose or responsibility.
DoH:	Department of Health.
DHIVA:	Dietitians working in HIV/AIDS.
Drug interaction (or drug–drug interaction):	A situation in which a substance (often another drug) affects the activity of a drug, i.e., the effects of the drug may be increased or decreased, or a new effect may occur that neither agent produces when taken on its own.
Genotype:	The genetic make-up of an organism, in this case HIV. Variations in genetic make-up will influence the susceptibility of HIV to various drugs.
GMC:	General Medical Council. www.gmc-uk.org
GU or GUM:	Genitourinary medicine. Medical specialty relating to the diagnosis and management of sexually transmitted infections (including HIV) and other genital conditions in men and women.
HDU:	High-dependency unit.
HIV:	Human immunodeficiency virus.
HIV drug resistance:	The ability of HIV to overcome the drugs used in its treatment. Other terms include class resistance and multi-drug resistance. Class resistance refers to a strain of HIV that shows evidence of resistance to one class of drug, e.g., NRTIs, NNRTIs or PIs. Multi-drug resistance usually implies resistance to multiple classes of drugs.
HIV resistance assay:	An assay to identify the presence of changes within the genetic make-up of HIV which will lead to drug resistance. It is useful in deciding which HIV drugs to use to treat HIV infection in an individual patient.

HLA-B5701: HLA-B5701 is one of a family of human genes, the human leukocyte antigen (HLA) complex. This particular HLA type is associated with allergic reactions to the drug abacavir.

HPA: Health Protection Agency. www.hpa.org.uk

HRG: Healthcare resource group.

ID: Infectious Diseases: The branch of medicine that specialises in the diagnosis and management of infectious diseases.

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

ITU: Intensive therapy unit.

“Late” and “very late” HIV diagnosis: A CD4 count below 350 cells/mm³ at time of diagnosis of HIV. Very late diagnosis is either clinical presentation of AIDS at time of HIV diagnosis or a CD4 count less than 200 cells/mm³.

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

Lymphocyte: White blood cells that play a central role in the body's immune responses. There are two main types of lymphocytes, B lymphocytes and T lymphocytes.

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

MDT/Multidisciplinary team: The term “multidisciplinary team” used in this document refers to a group consisting of representatives from several different professional backgrounds and areas of expertise. The membership of the group will vary depending on the patient population in which care is being provided. The membership should include key professionals who will contribute to improving and maintaining health for the patient population being served. Local MDT meetings should be held regularly within HIV services to provide an opportunity for professionals to review care plans for people with HIV attending the HIV service. MDTs are particularly important when the patient needs are best met through joint care involving more than one medical specialty, such as in pregnancy, adolescents, vulnerable persons and complex comorbidities.

Members of the MDT may not all be in one place at the same time and may operate within a virtual network. MDT care plan summaries should be documented in the patient’s clinical record.

The inclusion within multidisciplinary teams of non-clinical professionals and patients is essential for reviewing organisational care arrangements for an HIV service locally or regionally.

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

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

NHIVNA: National HIV Nurses Association. www.nhivna.org.

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

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

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

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

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

PA/Programmed Activity: A 3–4-hour unit of activity making up part of a consultant's work plan.

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

PEPSE: Post-exposure prophylaxis for HIV following sexual exposure.

PHE: Public Health England. www.dh.gov.uk/health/tag/public-health-england/

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

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

QIPP: The Quality, Innovation, Productivity and Prevention (QIPP) programme. This is a national Department of Health strategy involving all NHS staff, patients, clinicians and the voluntary sector. It aims to improve the quality and delivery of NHS care while reducing costs (see <http://www.improvement.nhs.uk/Default.aspx?alias=www.improvement.nhs.uk/qipp>).

RCP: Royal College of Physicians. www.rcplondon.ac.uk/

RHIVA: Rehabilitation in HIV Association.

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

STI: Sexually transmitted infection.

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

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

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

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

UNAIDS: The Joint United Nations Programme on HIV/AIDS (see www.unaids.org).

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

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

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

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

Appendix 4

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Mrs Jane Bruton	Chelsea and Westminster Hospital NHS Foundation Trust, London
Dr Fiona Burns	Royal Free Hospital NHS Trust, London
Mr Will Chegwiddden	Rehabilitation in HIV Association (RHIVA)
Dr Duncan Churchill	BHIVA
Mr Simon Collins	UK-CAB
Mr Ben Cromarty	North Yorkshire AIDS Action
Miss Michelle Croston	National HIV Nurses Association (NHIVNA)
Dr Hilary Curtis	BHIVA Audit and Standards Co-ordinator
Mr Paul Declé	Forum Link
Dr Valerie Delpech	Health Protection Agency (HPA)
Mr Alastair Duncan	Dietitians working in HIV/AIDS (DHIVA)
Dr Simon Edwards	BHIVA
Dr Meredith Elangasinghe	Sheffield Teaching Hospital NHS Foundation Trust
Dr Martin Fisher	BHIVA
Ms Claire Foreman	London Specialised Commissioning Group
Dr Andrew Freedman	BHIVA
Dr Stuart Gibson	British Psychological Society (BPS)
Dr Julia Greig	British Infection Association (BIA)

Dr Philippa James	Royal College of General Practitioners (RCGP)
Prof Margaret Johnson	BHIVA
Prof Saye Khoo	BHIVA
Prof Clifford Leen	BHIVA
Dr Nicola Mackie	BHIVA
Dr Alexander Margetts	British Psychological Society (BPS)
Mr Michael Marr	UK-CAB
Cllr Jonathan McShane	Local Government Association
Mr David Ogden	HIV Pharmacy Association (HIVPA)
Dr David O'Flynn	CASCAID, South London and Maudsley NHS Trust
Dr Ed Ong	BHIVA
Ms Kay Orton	Department of Health (Observer)
Dr Adrian Palfreeman	BHIVA
Mr Roger Pebody	UK-CAB
Ms Jess Peck	London Specialised Commissioning Group
Ms Karen Percy	Dietitians working in HIV/AIDS (DHIVA)
Ms Silvia Petretti	UK-CAB
Dr Anton Pozniak	BHIVA
Dr Cecilia Priestley	BASHH
Mr Jonathan Roberts	Brighton and Sussex University Hospitals NHS Trust
Dr Karen Rogstad	BHIVA
Prof Caroline Sabin	BHIVA
Mr Chris Sandford	Mortimer Market Centre, London
Dr Ewen Stewart	Royal College of General Practitioners (RCGP)
Dr Kevin Stewart	Royal College of Physicians (RCP)
Dr Jane Stockley	British Infection Association (BIA)
Ms Clare Stradling	Dietitians working in HIV/AIDS (DHIVA)
Ms Nimisha Tanna	Body & Soul
Dr Graham Taylor	Imperial College School of Medicine, London
Mr Robert Templeton	Social Care Institute for Excellence (SCIE)
Dr Melinda Tenant-Flowers	BHIVA
Mr David Walden	Social Care Institute for Excellence (SCIE)
Dr Ruth Wallis	Faculty of Public Health
Mr Paul Walsh	Corycia Ltd
Mr Paul Ward	Terrence Higgins Trust (THT)
Dr Zoë Warwick	Plymouth Hospitals NHS Trust
Dr Jonathan Wastie	St Peter's Medical Centre, Brighton

Dr Steven Welch	Children's HIV Association (CHIVA)
Dr Ed Wilkins	BHIVA
Dr Ian Williams	BHIVA
Mr Matt Williams	Monument Trust

■ Launch event steering group

Members

Prof Jane Anderson	BHIVA
Dr David Asboe	BHIVA
Dr Simon Edwards	BHIVA
Dr Martin Fisher	BHIVA
Dr Alastair Miller	BHIVA
Ms Silvia Petretti	UK-CAB
Dr Karen Rogstad	BHIVA

■ London: HIV care in 2012 workshop

Monday 12th March 2012, Royal College of Physicians, London

Attendance list

Dr Imtyaz Ahmed	Nottingham University Hospitals NHS Trust
Mr Alan Anderson	Positively UK
Prof Jane Anderson	BHIVA Project Co-Chair
Mr Will Chegwidan	Rehabilitation and HIV Association (RHIVA)
Miss Michelle Croston	National HIV Nurses Association (NHIVNA)
Dr Hilary Curtis	BHIVA Clinical Audit Coordinator
Dr Valerie Delpech	Health Protection Agency (HPA), London
Mr Alastair Duncan	Dietitians working in HIV/AIDS (DHIVA)
Dr Simon Edwards	BHIVA Project Co-Chair
Ms Claire Foreman	London Specialised Commissioning Group
Sir Muir Gray	NHS Right Care (QIPP)
Ms Tatiana Gray	TB Screening Team

Ms Camilla Hawkins	Mildmay Mission Hospital UK, London
Dr Anant Jani	NHS Right Care (QIPP)
Prof Margaret Johnson	Royal Free Hospital NHS Trust, London
Mr Francis Kaikumba	African Health Policy Network
Ms Ruth Lowbury	Medical Foundation for Aids and Sexual Health
Mr Richard Ma	Royal College of General Practitioners
Ms Susan McDonald	Imperial College Healthcare NHS Trust, London
Ms Esther McDonnell	Rehabilitation and HIV Association (RHIVA)
Ms Rebecca Mulin	Rehabilitation and HIV Association (RHIVA)
Dr Eleni Nastouli	Imperial College Healthcare NHS Trust, London
Dr Rebecca Nikurawo	Mildmay Mission Hospital UK, London
Mr David Ogden	HIV Pharmacy Association (HIVPA)
Ms Kay Orton	Department of Health
Sir Nick Partridge	Terrence Higgins Trust
Miss Sarah Payne	Berkshire Health Authority
Mr Roger Pebody	NAM
Ms Silvia Petretti	Positively UK
Ms Sarah Radcliffe	National AIDS Trust
Dr Iain Reeves	Homerton University Hospital, London
Mr Mark Santos	Positive East
Dr Nicki Saulsbury	Royal Cornwall Hospital
Dr Achim Schwenk	North Middlesex University Hospital, London
Dr Lindsay Short	Princess Royal Community Health Centre, Huddersfield
Dr Mehrunisha Suleman	NHS Right Care (QIPP)
Dr Christopher Taylor	King's College Hospital, London
Mr Robert Templeton	Social Care Institute of Excellence (SCIE)
Ms Marie Vieu	NHS Lambeth
Mr Paul Ward	Terrence Higgins Trust
Dr Amanda Williams	Children's HIV Association (CHIVA)
Dr Ian Williams	University College London Medical School
Ms Sarah Zetler	British Psychological Society (BPS)

■ Manchester: HIV care in 2012 workshop

Friday 11th May 2012, Midland Hotel, Manchester

Attendance list

Prof Jane Anderson	BHIVA Project Co-Chair
Dr David Asboe	Chelsea and Westminster Hospital, London
Dr Christine Bates	Royal Liverpool University Hospital
Dr Paul Benn	Central & North West London NHS Foundation Trust, London
Dr Christine Bowman	Sheffield Teaching Hospitals NHS Foundation Trust
Dr Alison Brown	Health Protection Agency (HPA), London
Miss Michelle Croston	National HIV Nurses Association (NHIVNA)
Dr Simon Edwards	BHIVA Project Co-Chair
Dr John Evans-Jones	Countess of Chester Hospital
Ms Claire Foreman	London Specialised Commissioning Group
Dr Julia Grieg	British Infection Association
Ms Jenny Hand	Leicestershire AIDS Support Services (LASS)
Dr Barbara Hedge	St Helen's and Knowsley Teaching Hospitals NHS Trust
Dr Philippa James	Royal College of General Practitioners
Dr Anant Jani	NHS Right Care (QIPP)
Mr Damian Kelly	George House Trust
Mr Tim Leaver	Corycia Ltd
Mr Paul Main	Rehabilitation and HIV Association (RHIVA)
Ms Pdraig McDonnell	British Psychological Society (BPS)
Dr Eric Monteiro	Leeds Teaching Hospitals Trust
Dr Angela Obasi	Liverpool School of Tropical Medicine
Mr Christopher O'Connor	Baseline
Dr Ed Ong	Royal Victoria Infirmary, Newcastle upon Tyne
Ms Adrienne Seed	THRIVINE
Mrs Lynda Shentall	George House Trust
Ms Sarah Stephenson	Manchester NHS Primary Care Trust
Mrs Clare Stradling	Dietitians working in HIV/AIDS (DHIVA)
Dr Ash Sukthankar	Central Manchester University Hospitals NHS Foundation Trust
Dr Mehrunisha Suleman	NHS Right Care (QIPP)

Dr John Sweeney	Royal Preston Hospital
Dr Toni Tan	North Manchester General Hospital
Dr Anjum Tariq	Royal Wolverhampton Hospitals NHS Trust
Dr Fiona Thompson	Northamptonshire Healthcare NHS Foundation Trust
Ms Helen Wallaston	The Sophia Forum
Dr Steven Welch	Children's HIV Association (CHIVA)

■ NHS right care (QIPP)

Members

Sir Muir Gray	NHS Right Care (QIPP)
Dr Anant Jani	NHS Right Care (QIPP)
Dr Mehrunisha Suleman	NHS Right Care (QIPP)

■ Community groups

Involvement in:

Standards working group

Terrence Higgins Trust
UK-CAB

Standards writing groups

Body & Soul
Forum Link
HIV i-Base
Monument Trust
National AIDS Manual (NAM)
National AIDS Trust (NAT)
North Yorkshire AIDS Action
Positively UK
Terrence Higgins Trust
UK-CAB

London workshop

African Health Policy Network

National AIDS Manual (NAM)

National AIDS Trust (NAT)

Positive East

Positively UK

Terrence Higgins Trust

Manchester workshop

Baseline

George House Trust

Leicestershire AIDS Support Services (LASS)

The Sophia Forum

THRIVINE

Responses to on-line public consultation

African Health Policy Network

Barnardo's

Baseline

Charity Bhengu

Forum Link

Global Friends Club Africa

National AIDS Manual (NAM)

National AIDS Trust (NAT)

North East London Sexual Health & HIV Network (NELNet)

Positive Catholics

Positively UK

South West London HIV & Sexual Health Clinical Services Network (SWAGNET)

South Yorkshire HIV Network

Surrey HIV Network

Terrence Higgins Trust

The AIDS Support Organisation – Uganda

The Rainbow Project

■ Public consultation

The on-line public consultation for the draft Standards of Care for People Living with HIV began on 12th September 2012 and ended on 7th October 2012.

The public consultation process via the BHIVA website received 155 feedback responses from a range of health care organisations, community groups, individual professionals and people living with HIV. All the feedback received during the consultation period can be accessed via the BHIVA website at www.bhiva.org.



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