

# Recommended standards for NHS HIV services

# Recommended standards for NHS HIV services

MEDICAL FOUNDATION FOR  
AIDS & SEXUAL HEALTH\*

Endorsed by  
Department of Health  
British HIV Association  
National Association of NHS Providers of AIDS Care and Treatment

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## Foreword

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As partners with the Medical Foundation for AIDS & Sexual Health (MedFASH) in the development of these recommended standards, we welcome their publication and are pleased to endorse them. We look forward to the positive impact we believe they will have on the quality of care for people with HIV in England.

HIV infection presents great difficulties for those living with the virus and tough challenges for those providing their care. While we have seen dramatic improvements in health and quality of life for many since the introduction of highly active antiretroviral therapy (HAART), we are also faced with sharp rises in the number of people infected and seeking care. The stigma and discrimination still associated with HIV are compounded by the social exclusion experienced by significant numbers of those infected. Their needs are not only for medication, but for a range of integrated health and social care services. About a third of those with HIV do not even know they are infected and risk severe illness following missed opportunities for diagnosis. New and developing HIV service networks should address these challenges, engaging professionals across disciplines and specialties along with people living with HIV.

This is, therefore, a particularly appropriate time to develop recommended standards for NHS HIV services. In these, providers will find a tool for planning and monitoring service development, commissioners a framework for reviewing and structuring resource allocation, and people with HIV a resource for facilitating access to consistent quality of care and partnership with care providers.

The process of developing this document has involved a wide range of individuals and organisations. As with any consensus document, there have been debates, disagreements and compromises. The recommended standards that have emerged from this process enjoy broad support, even though some differing views inevitably remain on individual points or omissions. We anticipate that the standards will feed into further work by different groups who wish to develop more detailed guidance or commentary on particular aspects of the document. This can only enhance the value and strengthen the impact of the recommended standards.

The recommended standards must continue to evolve, and we hope the range of views – from service users, providers and commissioners – will inform future revisions. Over time we expect the standards to play a pivotal part in the development and improvement of services for people with HIV.



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## Introduction

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These recommended standards are the result of a major project managed by the Medical Foundation for AIDS & Sexual Health (MedFASH). During their development, we benefited from the involvement of a wide range of organisations and individuals who volunteered their expertise, time and commitment. Their contribution has enabled us to produce recommended standards which are broadly supported by those providing, commissioning and using HIV services.

In setting up and managing this project, we drew on learning from earlier initiatives concerned with standards and networks for HIV services. We also undertook a parallel project to facilitate the development of HIV service networks. Working together in networks can help clinicians and other providers to meet shared standards of care, promoting service equity for people with HIV regardless of where they live. Delivery through service networks is therefore a cornerstone of these recommended standards, and users of the standards may find it helpful to refer to our guide to HIV service network development, to be published later in 2003.

MedFASH exists to promote excellence in the prevention and management of HIV and other sexually transmitted infections. We are grateful to have had this opportunity to influence the quality of NHS HIV services in England and we hope that, through implementation of the standards at local level, our efforts will contribute to improving the health and quality of life of people with HIV. We are eager for feedback on how the recommended standards are being used and would like to know about successes, but also about improvements which could be made to the standards in future. This must remain a living document, regularly reviewed to ensure it remains relevant and up-to-date.

Ruth Lowbury  
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## Executive summary

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*Improvement, expansion and reform: the next three years. Priorities and planning framework 2003-2006* highlights the importance of improving access to sexual health services as a means of reducing health inequalities. These new **Recommended standards for NHS HIV services** should facilitate such improvement and their development is one of the priorities in *The national strategy for sexual health and HIV*. The standards have been developed with the aim of enabling people with HIV in England to access the same quality of care wherever they live. The care pathway for people with HIV provides a framework for the standards, and the focus is on patient-centred care. The empowerment of people with HIV to manage their own health is an underlying principle. The views and experience of people with HIV, and the knowledge and expertise of professionals, have informed the development of these standards. Supporting evidence is identified in a list of relevant further reading.

These standards are a tool for commissioners, providers and people with HIV, to help them plan, develop, and audit HIV services. They will also be useful for performance management. They should be used in conjunction with the Department of Health's toolkit for primary care trusts (PCTs) and local authorities, *Effective commissioning of sexual health and HIV services*. As the pattern of service need changes along with our knowledge of how best to meet it, the standards should be regularly reviewed and updated.

*The national strategy for sexual health and HIV* states that all HIV practitioners will be expected to work within a managed service network. This way of working will be necessary to enable services to implement these standards. Networks provide a means of meeting the wide range of needs of people with HIV in a coordinated way, through structured collaborative working between the different services involved in their care. The **standard for managed HIV service networks** identifies some key principles and success factors for the development of networks and highlights the importance of partnership between the NHS, local authorities, the voluntary sector and service users in their planning and implementation.

The treatment and care of people with HIV should be coordinated with **HIV prevention (Standard 1)**. While not the primary focus of this document, a brief framework for prevention is presented, covering educational and behavioural interventions, the management of other sexually transmitted infections (STIs), provision of post-exposure prophylaxis (PEP) and avoidance of transmission in medical settings.

**Early diagnosis of people with HIV (Standard 2)** enables people with HIV to access treatment while it can be most effective. Late diagnosis is a major cause of illness and death among those with HIV in the UK, and a range of health professionals, including mainstream care providers, need to play a role in increasing early diagnosis. As part of this, the offer of an HIV test needs to become more routine in some settings and clinical situations.

**Empowering people with HIV (Standard 3)** relies on a partnership between service providers and users to manage their care. This can help people with HIV to get the most out of the services available to them, lead to improvements in their physical and mental health and enable them to cope better with the challenges of long-term living with HIV, including the associated stigma.

The **clinical care of people with HIV (Standard 4)** involves regular monitoring and often the provision of highly active antiretroviral therapy (HAART) which should be in accordance with British HIV Association (BHIVA) treatment guidelines. Specialist HIV care should be provided in conjunction with a range of medical specialties and support services. Local services can improve access to specialist care for socially excluded populations, although travelling to a more distant service may sometimes be necessary for specific types of therapy.

**Primary healthcare (Standard 5)** is provided by a range of healthcare workers whose patients will include people with HIV, whether their status is known or not. Important roles for primary care include earlier identification of people with HIV, providing general medical and dental care to complement specialist HIV care, and enabling people with HIV to access integrated health and social care services at local level.

These standards focus primarily on healthcare, but social factors can have an important influence on the health of people with HIV and their ability to use healthcare services effectively. The provision of **social care integrated with healthcare (Standard 6)** can therefore be a prerequisite for meeting clinical needs. Service quality can be improved through better coordination between health and social care, for example single assessments of individual need, and this can be fostered through integrated arrangements for planning and commissioning. This is not a comprehensive standard for HIV-related social care but it provides some principles particularly in relation to integration with healthcare.

Many people with HIV are sexually active. **Sexual healthcare (Standard 7)**, coordinated with their regular HIV care, can provide support for them to reduce the risks of acquiring other STIs, acquiring a further strain of HIV, or transmitting HIV to sexual partners. It can also provide specialist advice and help with related problems such as disclosure of HIV status to sexual partners, sexual dysfunction and treatment for STIs when needed. Sexual health risk assessment needs to be a regular part of ongoing health monitoring of people with HIV.

All pregnant women need to be offered and recommended a test for **HIV in pregnancy (Standard 8)**, in order to identify those who can benefit from interventions. This requires the participation of those providing routine antenatal care. A number of interventions before, during and after birth can maximise health outcomes and radically reduce mother-to-child HIV transmission. Their implementation requires multidisciplinary involvement, including social support. Consistency is needed in the availability of services for people with HIV requesting help to start a pregnancy with minimal risk of HIV transmission to their partner.

These standards are for adult services, but an increasing number of adults with HIV live in families, with children who may or may not be infected themselves. The **clinical and social care of families with HIV (Standard 9)** should be designed to meet the complex needs of both adults and children in a coordinated and seamless way. This requires multidisciplinary and multi-agency working to provide services at local level, with access through service networks to more specialist expertise, perhaps at a distance. Family needs change over time and family services can support the transition to adolescent care as children get older.



HIV-related emergencies may be life-threatening and occur in those who are aware of their infection but especially in those still undiagnosed. The **emergency care of people with HIV (Standard 10)** requires a range of medical expertise, with access to high level care and support services, and 24-hour access to HIV specialist clinical support. Emergency services should be familiar with HIV-related conditions, in order to maximise the rate of diagnosis among those still unaware of their infection, and to ensure the most appropriate emergency and ongoing HIV care.

The **care of people with HIV during admission to hospital (Standard 11)** should be undertaken with the involvement of a specialist HIV centre and should include access to a full range of support services and medical specialties. Availability of critical care facilities for those who are critically unwell, and negative-pressure isolation facilities for those with proven or suspected tuberculosis (TB), is important. Coordination of discharge planning should be multidisciplinary, based on assessment of social, psychological and clinical care needs.

Despite improved health outcomes resulting from antiretroviral therapies (ARTs), some people with HIV still experience late or end-stage disease and need **respite, rehabilitation and palliative care (Standard 12)**. Those with alternating periods of remission and exacerbation can benefit from periods of respite care. People with HIV-related cognitive impairment should have access to specialist rehabilitation following assessment of suitability. Because the course of disease is not always predictable, palliative and curative approaches need to be integrated. End of life care for those with HIV requires expertise in palliative care as well as some HIV-specific skills and knowledge, including an understanding of psychosocial aspects, such as stigma, and the cultural diversity of populations affected by HIV.

## Table of recommended standards

<p><b>Standard for managed HIV service networks:</b> All people with HIV should have access to services which operate within a managed service network in order to achieve the best possible treatment and care for individuals as close as possible to where they live</p>	<p><b>Standard 1:</b> HIV prevention</p>	<p>A comprehensive evidence-based HIV prevention programme, integrated with other initiatives to promote sexual health and reduce transmission of blood borne viruses, should complement and involve HIV treatment and care services.</p>
	<p><b>Standard 2:</b> Early diagnosis of people with HIV</p>	<p>The NHS should develop, implement and monitor strategies to encourage the uptake of testing and reduce the number of people who are unaware of their infection.</p>
	<p><b>Standard 3:</b> Empowering people with HIV</p>	<p>All care should take place in a partnership between people with HIV and care providers so that there is joint decision-making and support to adopt and maintain a healthy lifestyle. Services should recognise the impact of HIV infection on an individual and the stigma and social exclusion unique to HIV.</p>
	<p><b>Standard 4:</b> Clinical care of people with HIV</p>	<p>All people with HIV should have access to comprehensive specialist HIV treatment and care services and to a full range of supporting services and medical specialties. All these services should be available irrespective of the site of care.</p>
	<p><b>Standard 5:</b> Primary healthcare for people with HIV</p>	<p>People with HIV should have access to good quality primary healthcare provided by local networks, that are sensitive to the needs of those living with HIV.</p>
	<p><b>Standard 6:</b> Social care integrated with healthcare for people with HIV</p>	<p>All people with HIV should have access to social care services which are responsive, culturally appropriate and tailored to individual need. All people with HIV requiring multi-agency support should receive integrated health and social care.</p>
	<p><b>Standard 7:</b> Sexual healthcare for people with HIV</p>	<p>All people with HIV should receive comprehensive sexual healthcare integrated with their HIV specialist care.</p>
	<p><b>Standard 8:</b> HIV and pregnancy</p>	<p>The NHS should develop, implement and monitor policies that seek to empower and support pregnant women with HIV to maximise their health and reduce mother-to-child transmission of HIV.</p>
	<p><b>Standard 9:</b> Care of families with HIV</p>	<p>Children, their families and carers should have access to specialist adult and paediatric multidisciplinary care including community care and support.</p>
	<p><b>Standard 10:</b> Emergency care of people with HIV</p>	<p>All people with HIV should have prompt access to rapid and effective treatment of all emergencies (HIV and other) by appropriately trained clinical healthcare workers.</p>
	<p><b>Standard 11:</b> Care of people with HIV during admission to hospital</p>	<p>All people with HIV should have access to comprehensive specialist HIV inpatient treatment and care services and to a full range of supporting services and medical specialties.</p>
	<p><b>Standard 12:</b> Respite, rehabilitation and palliative care for people with HIV</p>	<p>People with HIV should have access to palliative and respite care services that are sensitive to their specific needs at different stages of disease. Access to rehabilitation services for those with HIV-related cognitive impairment should be dependent on their current needs and their potential to improve.</p>



## Chapter 1: Setting the scene

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### Introduction

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- 1 This document, endorsed by the Department of Health (DoH), supports implementation of the Department's policy on HIV.
  - *The national strategy for sexual health and HIV*, and its implementation action plan, include the development of standards as a key action point.
  - The toolkit for primary care trusts (PCTs) and local authorities, *Effective commissioning of sexual health and HIV services*, states that recommended standards should underpin the planning and delivery of services to communities disproportionately affected by sexual ill-health and HIV.
  - Such standards provide a tool to facilitate improvements in access to sexual health services, a priority identified for the NHS in *Improvement, expansion and reform: the next three years. Priorities and planning framework 2003-2006* (under the heading of *Reducing health inequalities*).
  
- 2 These **Recommended standards for NHS HIV services** are therefore presented as a tool for change to enable more people to live free of HIV, more people to live free from the progression of HIV disease and its consequences, and fewer people to die as a result of an HIV-related condition.
  
- 3 To achieve these goals, HIV services should be:
  - *person-centred*: empowering the individual to make healthy choices and to manage their own HIV, through education and support which recognises the importance of lifestyle, culture and religion, and which, where necessary, tackles the adverse impact of material disadvantage, social exclusion and stigma
  - *developed in partnership*: so that goals and the respective responsibilities of the individual and the medical and social support services are agreed and clearly set out in a regularly reviewed plan
  - *equitable*: so that services are planned to meet the needs of the population, including specific groups within the population, and are appropriate to people's needs
  - *integrated*: drawing on the knowledge and skills of health and social care professionals across a multidisciplinary HIV healthcare team, including primary care and social care as well as specialist services
  - *outcomes oriented*: narrowing the inequalities gap between those groups whose outcomes are poorest and the rest, minimising the risk of acquiring HIV and associated complications, and maximising the quality of life for service users by empowering staff to deliver, evaluate and measure care.

- 4 Delivering this vision and embedding these principles in practice requires staff throughout health, social care and community organisations to understand the experience of HIV and HIV care, and to recognise the expertise of people living with HIV. The aim will be to empower people with HIV through skills, knowledge and access to services to take control of the management of their own HIV infection and fulfil their potential to live long lives free of the complications that can accompany HIV.
- 5 This is a living document, informed by evidence and by the experience of service users, providers and commissioners at the time of writing. If the standards are to remain a useful tool, they should be regularly reviewed and updated.

## Why standards?

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- 6 This country has had success in responding to HIV. With innovative prevention activities initiated early in the epidemic, rates of infection have been kept at a level lower than in many other European countries. On the treatment front, since the introduction of HAART in the mid-1990s, death rates have declined dramatically and the majority of people with HIV are managing to live in relatively good health. An audit of the BHIVA guidelines for HIV treatment has shown that their implementation is widespread.
- 7 However, HIV still presents major challenges for those living with the virus and those working in prevention, treatment and care.
  - New infections continue to occur, despite prevention efforts, and there are more people now living with HIV than ever before.
  - Almost a third of people with HIV remain undiagnosed, sometimes with signs and symptoms overlooked by healthcare workers until they become critically ill.
  - HAART can be demanding to take, with potentially unpleasant side-effects, and people with HIV often need support to adhere to treatment.
  - The long-term effects of antiretrovirals are still unknown, but the development of drug resistance and complications requires increasingly complex drug combinations and treatment monitoring.
  - New population groups are affected, often with complex care needs, and they are increasingly moving to parts of the country with relatively little experience of HIV.
  - There is still no vaccine or cure, and HIV disease remains potentially fatal.
- 8 The development of recommended national standards is an important part of the NHS modernisation programme, a tool for achieving consistency, equity of access and high quality care. *The national strategy for sexual health and HIV* identifies the unequal impact of HIV on different population groups, and the varied quality of sexual health services across the country as significant concerns. These standards for NHS HIV services are supported by the DoH as part of the implementation of its strategy to tackle such inequalities.
- 9 The new services standards are designed to complement the BHIVA treatment guidelines and to be applicable to all service settings, in areas of England with both high and low HIV prevalence. They should serve as a tool for achieving equity of access to services for all service users and consistent quality of care regardless of the point of access.

## What are HIV and AIDS?

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- 10 HIV is a virus that compromises the human immune system and impedes its ability to fight infection. Through processes that are still not fully understood, the virus copies its genetic material into the genetic material of human cells. HIV is able to infect key cells (CD4 cells) which coordinate the immune system's fight against infection.
- 11 AIDS is a syndrome resulting from the damage caused by HIV. When a person with HIV is diagnosed as having AIDS, this means they have one or more of a defined list of otherwise usually rare illnesses as a result of the breakdown of the body's immune system. These illnesses are mostly opportunistic infections (especially TB or pneumonia) or cancers. The AIDS-defining list used in England applies across Europe and was last modified in 1993.
- 12 The introduction of HAART since 1995 has resulted in HIV infection becoming more controllable. It has become possible to reduce the levels of HIV (viral load) in the blood, and to stimulate the continued presence of key immune-boosting cells (CD4 count). This can result in a return to health of people previously suffering HIV-related ill-health, or a delay in the onset of illness for those not yet symptomatic.
- 13 In this context, the term 'AIDS' is becoming less meaningful. It is still used as a category for surveillance, but in clinical practice, it is increasingly possible to develop an 'AIDS-defining' illness and have it successfully treated, or to be very unwell with HIV but not have AIDS. Because of this, use of the term 'AIDS' is decreasing among healthcare workers in this country, in favour of terms such as 'symptomatic HIV'. This document will follow the trend.
- 14 Strains of HIV with resistance to one or more of the antiretroviral drugs are becoming more prevalent. The resulting failure of the standard drug regimen in some people with HIV necessitates more complex and expensive treatment and a gradual reduction in the available treatment options. Resistant virus can also be transmitted from one person to another, so that some people who are newly diagnosed are resistant to certain drugs before they even start treatment. In addition, it is now clear that after infection with HIV, an individual can be infected with new strains of the virus which may be resistant to antiretroviral drugs or may lead to more rapid progression of disease. Strict adherence to difficult regimens is required to reduce the risk of drug-resistance developing, and antiretroviral drugs can also have severe side-effects. All these facts temper the optimism associated with the vastly improved health of those on HAART.

## Who gets HIV and how?

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- 15 In 2001, there were 4,909 new diagnoses reported in the UK, of which 4,661 (95%) were in England – the highest annual total since the beginning of the epidemic. This increase in new diagnoses, combined with the reduction in HIV-related deaths as a result of HAART, has resulted in growing numbers of people living with diagnosed infection. In England, this growth was from 13,446 in 1996 to 20,855 in 2000 and 24,269 in 2001 (annual prevalence figures – not adjusted for under-reporting). It is estimated that the total number of HIV-infected people alive in the UK at the end of 2001 was about 41,200, of whom almost a third (12,900) had not yet had their infection diagnosed.

- 16 The groups most affected by HIV in England are gay men and people who are from or have been living in certain high prevalence African countries. The vast majority of the latter are believed to have acquired the infection through heterosexual sex.
- 17 The annual prevalence survey shows that gay men constitute the largest number of HIV infected people within the UK. In the 10 years from January 1992 there were almost 15,000 new diagnoses of HIV infection acquired through sex between men. Although some of these will have been acquired earlier in the course of the epidemic, there is substantial evidence pointing to continuing transmission. New diagnoses are occurring in all age groups.
- 18 There has been a rapid rise in new diagnoses of infections acquired through sex between men and women. Around three-quarters of these each year are now in people from, or who became infected in, sub-Saharan Africa. In the early 1990s people from Uganda were the biggest group affected, but in more recent years there have been increases in new diagnoses from other African countries, especially Zimbabwe. Many of these HIV infections affect families, and children of infected adults may or may not be infected.
- 19 The number of people newly diagnosed each year whose only risk for acquiring HIV is heterosexual sex within the UK is small but rising, making up around 10 per cent of new heterosexual diagnoses.
- 20 Although the potential still exists for HIV transmission through injecting drug use there is no evidence of significant current spread amongst injecting drug users in the UK. Data suggest that about 1 per cent of injecting drug users in contact with drug agencies have HIV. There is little doubt that, were it not for needle exchange programmes and other harm minimisation activities, this country would have seen much larger numbers of HIV-infected injectors. However, the percentage of injecting drug users sharing needles or syringes is much higher than 10 years ago, following a dramatic rise during the late 1990s; and transmission of other blood borne viruses, such as hepatitis C, continues at a much higher rate than HIV.
- 21 The proportion of pregnant women who are infected with HIV has increased steadily in all areas of England, with the infection rate highest in inner London but increasing most outside it. Of those delivering in London and outside it 0.35 per cent and 0.04 per cent respectively were infected with HIV in 2001. Although preventable HIV infections are still occurring in children, there has been a steady increase in the proportion of HIV-infected women diagnosed before delivery. This is of great public health importance, since interventions can reduce the risk of mother-to-child transmission of HIV from between one in three and one in four to less than one in 100. During 2001, an estimated 85 per cent of HIV-infected pregnant women in London were diagnosed before they gave birth, exceeding the DoH's national target of 80 per cent by 2002. In the rest of England, an estimated 64 per cent of pregnant women had their infection diagnosed prior to delivery.
- 22 Five healthcare workers have acquired HIV through occupational exposure (needlestick injuries, etc) within the UK, and a further 12 healthcare workers working in high prevalence countries (some originally from the UK) have acquired HIV through needlestick injury abroad and have been diagnosed in the UK. Occupationally acquired HIV infection may be prevented

by a four week course of antiretroviral drugs started very promptly after exposure, known as post-exposure prophylaxis (PEP).

- 23 The geographic distribution of HIV infection is very uneven across England. London, Brighton and Manchester are the cities with the largest HIV-infected populations, although other metropolitan areas have significant numbers. Some 60 per cent of the UK's diagnosed people with HIV are resident in London. The unlinked anonymous testing programme shows that, among people attending genitourinary medicine (GUM) clinics, rates of HIV are six times higher among gay men, and seven times higher among heterosexual men and women, in London than in the rest of England and Wales.
- 24 Inevitably, the profile of the UK HIV epidemic reflects the prevalence of HIV around the world. The majority of UK-diagnosed infections acquired overseas occur in people from sub-Saharan Africa. Some increase in new diagnoses amongst black Caribbeans has occurred in the last five years but the numbers are small, and although the HIV epidemic in the Indian sub-continent has grown in recent years, this as yet has had little impact in the UK. Each year HIV infection is diagnosed in a number of people who have travelled and had sex abroad, especially in South East Asia (for instance, 152 UK diagnoses in men during 1997-2001 were attributed to exposure in Thailand).
- 25 While much is now known about who gets HIV and how to treat them, it must be stressed that almost a third of those estimated to be living with HIV have not yet been diagnosed. While undiagnosed, these individuals cannot benefit from early access to treatment and may be more likely to transmit the virus to others. There are significant numbers of people attending GUM clinics with an acute sexually transmitted infection (STI) whose HIV remains undiagnosed and of mothers whose HIV is not diagnosed before giving birth. Many HIV diagnoses are still made late in the course of disease progression, a significant number so late that treatment has no time to take effect before the person with HIV dies.

## The personal and social cost of HIV

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- 26 As a lifelong and potentially fatal condition, HIV can have a major impact on lifestyle, relationships, work, income, health, wellbeing and life expectancy. Treatment can be complex and demanding and side-effects common. Poor psychological adjustment can create barriers to effective disease management. The continuing stigma and poor public understanding of HIV can increase isolation and fear of disclosure, leading to failure to access appropriate medical and social support services. The impact of HIV often compounds the vulnerability and social exclusion of the population groups it most frequently affects.
- 27 Although many people with HIV are finding it possible to return to, or continue in, full-time employment or education, those who are unable to do so can face financial pressures as a result of their HIV diagnosis. Many people with HIV feel the benefits system is not responsive to the peculiarities of HIV in the era of HAART. Asylum seekers with HIV face particular material difficulties (see below at 49-51).
- 28 Since HIV affects mainly younger adults, it is associated with a high number of potential years of life lost.



- 29 HIV also has a significant impact on health and social services:
- the average lifetime treatment costs for an individual are calculated to be between £135,000 and £181,000
  - the average annual cost per person of service provision for those on HAART is approximately £15,000
  - the overall cost of treatment is increasing, due to the rapidly rising number of people diagnosed with HIV, the longer survival of those on treatment, the more extensive monitoring, and the use of four, five or more drugs in salvage therapy for those who have failed several drug regimens.
- 30 However:
- the monetary value of preventing a single transmission is estimated to be between £0.5 and 1 million in terms of individual health benefits and treatment costs
  - provision of combination ART has been shown to have a significant benefit in terms of cost effectiveness and quality of life
  - it has been estimated that between £4,000 and £13,000 of annual indirect costs (disability-related unemployment benefits, loss of economic productivity, community and informal services) could be saved for each individual whose HIV disease is prevented from progressing from non-symptomatic to symptomatic HIV, or from symptomatic HIV to AIDS.

## The development of new standards for NHS HIV services

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- 31 The development of national standards is an important part of the NHS modernisation programme, as set out in *The NHS Plan* and follow-up documents. They are described as a tool for eliminating the 'lottery of care' which undermines public confidence in the NHS. Modern approaches to the delivery of care include innovative care pathways, which better meet patients' needs and the development of networks for the provision of care across organisations. Reflecting these priorities, *The national strategy for sexual health and HIV* states that all HIV practitioners will be expected to work within a managed service network and promises the development of updated standards for HIV treatment and care services.
- 32 These standards for NHS HIV services build on learning from earlier work, including the *Standards for NHS hospital HIV services* published in 1998 by the BMA Foundation for AIDS, now known as the Medical Foundation for AIDS & Sexual Health (MedFASH). The new standards adopt a modern approach, using as a framework the care pathway for people with HIV and highlighting the role of service networks in meeting standards. In this, they draw on clinical and organisational approaches from other fields, in particular the national service framework (NSF) standards for diabetes, as well as the managed service network model adopted for cancer and other areas of healthcare in England and Scotland. The key principle informing this document is that the focus is always on the service user and how to meet their needs – patient-centred care as advocated in *The NHS Plan*.
- 33 A national advisory group developed the standards (see Appendix C for membership). A larger national stakeholder group of organisations with an interest in HIV, and three consultation groups in different locations in England, commented on the initial drafts of the standards (see

Appendix D for locations of groups and list of stakeholder members). The development process was managed by MedFASH, with funding from the Department of Health, London health authorities, British HIV Association (BHIVA) and National Association of NHS Providers of AIDS Care and Treatment (PACT).

## The standards

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- 34 The standards aim to:
- define a level of care that is achievable in all parts of England
  - facilitate equity of access to services for all people with HIV
  - provide a framework for consistent and high quality care at all points of the care pathway
  - facilitate equitable partnerships between the service user and the HIV service provider
  - build further on multidisciplinary collaboration across health and social care sectors, to enable seamless provision of care through a managed network, whatever the point of access
  - promote an outcomes-orientated approach to care.
- 35 The standards provide a tool for both commissioners and service providers, to help them plan, develop and audit service quality. They also indicate to service users the standard of care they can expect.
- 36 To implement the standards, it is recommended that individual services work within a managed service network. Such a network should plan services collaboratively, with the involvement of service users as well as commissioners and providers from the statutory and voluntary sectors. A network should ensure the different services provided within it are complementary, and that network-wide services are provided where appropriate (eg access to 24-hour specialist advice for emergency care). Aspects of service audit and monitoring may also best be undertaken across a whole network, for example surveys of service user satisfaction or reviews of HIV-related deaths.
- 37 A patient-centred care pathway approach is central to the design and development of these standards. At each stage of the care pathway, with entry from a range of access points, the service user should be able to expect and receive consistent standards of care. The pathway in the standards moves from prevention, via primary and acute secondary care, through to terminal care.
- 38 For each standard along the care pathway, this document:
- summarises what is needed and what works
  - identifies key interventions
  - indicates the implications for service planning
  - identifies existing guidance or expert consensus on good practice
  - suggests indicators which can be used to measure performance
  - provides a short list of relevant supporting papers, mostly relating to evidence of effectiveness.

## Supporting evidence

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- 39 The views and experiences of people with HIV, and the knowledge and expertise of HIV practitioners, have informed the development of these standards. Published supporting evidence has been identified and Appendix A includes a short list of relevant papers and further reading for each standard. The amount and the robustness of available evidence varies from standard to standard and this document does not attempt to categorise it or review it systematically. Much research now has limited relevance because it dates from the period before HAART. Further work would be useful to build a more solid evidence base, both by implementing a more thorough review of existing evidence and by undertaking new research on the implications of service organisation for health outcomes.
- 40 In the fast-moving world of HIV, the evidence base is rapidly evolving, and regular review will be important to identify key new findings and consider their implications for updating the standards. This should include the implications of new, evidence-based guidelines for clinical effectiveness, such as those from BHIVA or the Clinical Effectiveness Group of the Association for Genitourinary Medicine (AGUM) and the Medical Society for the Study of Venereal Diseases (MSSVD). A review in due course of the impact of these standards, including the perceptions of service users and providers, may also highlight further areas where research is needed.

## Scope of the standards

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- 41 These standards were initiated to apply to HIV treatment and care services for adults in the NHS. During their development, it became clear that in adopting the integrated approach to service delivery, through service networks, it would not be possible to draw a fixed boundary around these particular services. Children live in families with adults, and services for each may be linked or combined. The provision of social care by providers in local authorities and the voluntary sector needs to be planned and commissioned in an integrated way with the provision of healthcare, in order to ensure the best outcomes for people with HIV. There is a clear prevention role for providers of treatment and care and of HIV testing, and their work needs to be set against a backdrop of a broader prevention programme.
- 42 For this reason:
- a standard for family services is included – not a standard for paediatric care, which would be outside the scope of this project, but one which addresses the needs of adults and children together and is designed to complement standards for paediatric care being developed elsewhere (see Standard 9)
  - a standard for social care, integrated with healthcare, is included which addresses both the commissioning and providing role of local authorities in line with the Health Act 1999 (see Standard 6)
  - a standard for prevention is included which sets out broad principles designed to support more detailed guidance for sexual health promotion and HIV prevention available elsewhere (see Standard 1)
  - in a number of the standards, a role for the voluntary sector is identified which should complement statutory services in ways to be determined at local level.

- 43 Treatment and care of adults within the NHS remain the primary focus of the recommended standards. However, this does not mean they only address the role of hospital-based specialist HIV services. With the aim of ensuring equity of access for all people with HIV, and equity of care along the whole care pathway regardless of point of access, the standards apply not only to hospital-based specialist services but to the full range of NHS provision. A few implications of this are highlighted in 44 to 55 below.

### Service user choice

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- 44 Throughout these standards the focus is on the person with HIV, their needs and the care they can expect to receive. In other areas of healthcare, the government has highlighted the importance of patient choice, and HIV services have traditionally been at the forefront of providing this aspect of quality care. Individuals requiring an HIV test, or treatment and care for their HIV, can choose which clinic they wish to attend and are not obliged to use the service in their local area. This is of great importance because of the continuing stigma and discrimination associated with HIV which might put some people off attending services, and because of the diversity of the population groups affected. Open access provision, enabling individuals to choose which service to attend, may provide the additional reassurance about confidentiality or anonymity needed to motivate people to use services. It can also give the opportunity for different population groups, such as gay men or African families, to access services particularly suited to their needs. It is recommended that this aspect of HIV service provision be maintained, in order to sustain and improve quality of care and equity of access.

### Primary healthcare

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- 45 The number of people living with HIV in England is increasing, many living long and relatively healthy lives with the benefit of HAART. They need general primary healthcare as does the rest of the population, and general practitioners (GPs) and the primary care team will increasingly see people with chronic diagnosed HIV infection. The antenatal HIV screening programme has been successful so far in ensuring that the majority of pregnant women are routinely offered HIV tests. Primary care has a role in this. Furthermore, there is a need for earlier diagnosis of HIV in those who do not suspect they may be infected. Members of the primary care team are among the healthcare providers most likely to be approached by such individuals with unexplained symptoms, and increasing the offer of HIV testing in this setting would therefore bring clear benefit. In summary, there is a clear role for providers of primary healthcare within HIV service networks and this is reflected in several standards, particularly Standard 5.

## People in prison

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- 46 The number of people with HIV in English prisons is much lower than in some European countries, but the potential for HIV transmission in prison, or soon after release, remains. The principles of good practice in HIV prevention, based on evidence of effectiveness, need to apply as much to those in and leaving prison, or young offender institutions (YOIs), as to the rest of the population.
- 47 For those infected, access to the same standards of diagnosis, treatment and care should be a guiding principle. This is in line with the Prison Service Performance Standard 22, *Health services for prisoners* (last revised July 2002), which has as its stated objective: 'To provide prisoners with access to the same range and quality of services as the general public receives from the National Health Service (NHS)'. In practice, this should mean not only ensuring that people in prison or YOIs have access to appropriate medical care, but also that other aspects of their living conditions do not compromise the quality of that care or their ability to benefit from it. For example, the importance of adherence to strict treatment regimens makes it essential that people with HIV in prison are always able to take their medication at the right times of day, without interruptions to treatment, and that any associated dietary requirements are met. The need for regular monitoring and a consistent supply of complex medication makes continuity of care essential when people with HIV are transferred between prisons or released.
- 48 There will necessarily be variations in the application of the standards between prisons. However, the priority must be that the principle of each standard is applied to every prison setting in England and that there is consistency and coherence in their application across all aspects of the prison service.

## Services for asylum seekers

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- 49 Some asylum seekers come from countries with high HIV prevalence and a number are HIV-positive, some still undiagnosed. Healthcare providers need to be alert to the possibility of HIV infection and the benefits of early diagnosis.
- 50 Asylum seekers may be dispersed to parts of the country with low prevalence of HIV, little experience of managing HIV infection in women and children, and no appropriate community-based support services in place. Accommodation may give little privacy, eg for storing and taking complex medication, and levels of financial support may prevent the purchase of appropriate healthy food or transport to HIV treatment and care clinics. Since 3 March 2003, asylum seeking pregnant women and children up to the age of three who are supported by the National Asylum Support Service (NASS) have been eligible for additional payments for milk or infant formula, to help avoid transmission via breastfeeding (see Standard 8). The circumstances of asylum seekers' lives, including the trauma that may have led to their move to the UK, can result in complex mental healthcare needs.
- 51 Asylum seekers are entitled to NHS treatment. The principle of equity of access and quality of care makes it important for local commissioners and providers to address the particular

needs of the asylum seeker population. As with people in prison, facilitating continuity of care in terms of treatment and monitoring should be a central plank of service provision for asylum seekers with HIV.

### Services for injecting drug users

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- 52 Injecting drug users who have HIV may be using statutory and/or voluntary sector services in relation to their drug use, for drug treatment or for needle and syringe exchange and other support. It is important for these drugs services to be included in the HIV service network, and for their staff to be aware of the local specialist HIV services and understand the implications of HAART for their users. Drug users should be able to access HIV services as easily as other members of the population and to receive the same quality of care, provided in a manner responsive to their often complex social and psychological needs.

### Services for people with HIV and other medical conditions

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- 53 People with HIV and haemophilia may receive most of their HIV care from a haemophilia centre. It is important that these standards apply to care in this context and this means that haemophilia centres should be part of HIV service networks, with access to HIV specialist advice and referral when needed. Clear referral pathways should also be in place to enable people with HIV and haemophilia to access aspects of HIV care which may not be provided within haemophilia centres, such as sexual healthcare.
- 54 Similar considerations may apply to people with HIV who are co-infected with hepatitis B or C, or with TB, if their care is coordinated by hepatologists or respiratory medicine specialists respectively. Co-infection can make treatment of both infections more complex and joint care is recommended.

### Mental healthcare

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- 55 The standards address all aspects of healthcare for people with HIV, including mental healthcare. Many people benefit from psychological support with issues such as adjusting to a new HIV diagnosis, maintaining safer sex, or adhering to HAART. A smaller number need care for serious psychiatric problems, but people with HIV are more likely than the general population to experience serious mental illness. Whether provided by liaison psychiatry for those admitted to hospital or by community mental health teams for those in the community, the mental healthcare of people with HIV should be coordinated with the rest of their health and social care. This may present difficulties when people are using HIV services outside the catchment area for their local mental health services, highlighting the importance of including mental health services in HIV service networks.

### Reducing inequalities

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- 56 HIV impacts on communities that may already suffer health inequalities and discrimination because of their sexuality, race or lifestyle. Particularly vulnerable groups are gay men, people from black and minority ethnic communities, asylum seekers, injecting drug users and

people in prison. Research with people with HIV has found a significant proportion reporting personal experience of discrimination from healthcare providers. There is a need to facilitate equity of access to treatment in settings free from stigma and discrimination, and the provision of good quality care for all, responsive to individual needs.

- 57 The stigma associated with HIV, and the sensitivity relating to its major routes of transmission, have highlighted the importance of confidentiality in this area of care. High standards of confidentiality should apply in all services for people with HIV, statutory and voluntary, in line with guidance from the DoH and professional regulatory bodies, with clear protocols for recording and sharing of patient information, and explicit guidance on obtaining patient consent for this. Publicising policies on service confidentiality can provide reassurance for actual and potential service users and encourage use of services. It will be important for HIV service networks to ensure that any concerns about confidentiality, particularly between statutory, voluntary and service user organisations, are addressed in a way that prevents them serving as an obstacle to network development.
- 58 The cultural, religious and linguistic backgrounds of people living with HIV in England are diverse, as are the lifestyles. For service providers to engage effectively with service users they should have an understanding of the particular difficulties and needs of the population groups they work with, and an ability to respond appropriately. It is recommended that the provision of specific services such as advocates, interpreters and materials in different languages and formats, be part of service planning and implementation, informed by local needs assessment.

## Involving people with HIV

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- 59 Integral to these standards is the principle of empowering people to take control of their health, including the management of their HIV. The importance of involving people with HIV in the planning and monitoring of services is also highlighted. Some people with HIV were involved in the development of these standards, but finding ways to facilitate the participation of individuals from the range of population groups affected remains a challenge, especially those groups which are most socially excluded. Service planners should include community participation in the development of local service networks, and innovative ways need to be found to do this. The involvement of people with HIV, and communities affected by HIV, should be integral to the process of reviewing the recommended standards as perceptions of their impact on service quality may be different from that of providers.

## Training and continuing professional development

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- 60 Throughout the standards there are implications for training and professional development. Different types of training are appropriate depending on the competencies needed or intensity of involvement in HIV. Those specialising in HIV are likely to need dedicated training courses and hands-on experience to develop skills as well as continuing professional development activities such as educational meetings, audit, and reading of journals.
- 61 For doctors, only the specialties of GUM and infectious diseases have curricula for HIV as a

core part of their specialist training programmes. A diploma in HIV Medicine is being developed by the Society of Apothecaries in collaboration with BHIVA and the MSSVD. Although this will only entail a single assessment it will be available to a wide range of doctors who have responsibility for caring for individuals with HIV infection. For post-registration nurses, there is no single standard specialist HIV training course universally available. Some universities offer the curriculum previously approved by the former English National Board for Nursing, Midwifery and Health Visiting (ENB), but provision is very variable around the country. A range of alternative multidisciplinary training, which nurses can access, is available throughout the country and addresses aspects of HIV prevention, treatment and care.

- 62 As well as clinical knowledge and skills, healthcare workers need awareness and understanding of social, psychological and cultural issues affecting individuals and population groups affected by HIV. Training on ethical and attitudinal issues, such as confidentiality or being non-judgemental, are particularly important in view of the stigma associated with HIV. This type of non-clinical training is recommended for all those providing care for people with HIV, not only clinicians.
- 63 Healthcare workers in settings where HIV is not the main focus of work, such as primary healthcare, accident and emergency departments (A&E) or general medical wards, would benefit from training to develop a basic level of awareness about the aspects of HIV they may come across, such as identifying undiagnosed infection, as well as a grounding in relevant attitudinal and ethical issues.
- 64 HIV service networks can play an important part in continuing professional development, through structured opportunities for learning such as network educational meetings and through the more informal sharing of knowledge and experience between those liaising on aspects of care for people with HIV.

## Professional roles and HIV specialists

- 65 The multidisciplinary approach has been a lynchpin of HIV care, and this is reflected in these standards. To achieve good quality, integrated care requires the involvement of doctors, nurses, midwives, health advisers, psychologists, counsellors, dentists, dieticians, pharmacists, other professions allied to medicine, social workers, people with HIV themselves and many others. Among these will be some with particular expertise in HIV who might be called 'HIV specialists' and others whose role is more generalist, or specialist in other areas, but who will sometimes play a part in HIV care.
- 66 During the development of these standards, which refer frequently to 'HIV specialist' services or clinicians, the question was often raised: 'What is a specialist in HIV?' HIV medicine is not in itself a specialty recognised by the General Medical Council (GMC). In the absence of such formal status, it would be inappropriate for this project to attempt a formal definition requiring at the least the establishment of an agreed list of clinical competencies. Instead, the project has advised the Royal College of Physicians of the view expressed by a number of stakeholders that a definition would be helpful, and suggested that the Royal College, as the



appropriate body, should liaise with the relevant professional groups on how to take this forward. Nevertheless, the frequent use of the term in the standards, and the importance placed within them on ensuring 'HIV specialist' involvement in certain aspects of care, require some elaboration of the concept here.

- 67 Because of the diversity of HIV-related clinical conditions, a variety of medical specialties are needed within an HIV service network. However, the lead clinician of any 'specialist HIV treatment and care clinic' or 'specialist HIV centre' would normally be a physician with specific knowledge and experience of HIV.
- 68 A number of terms relating to HIV specialism are used in the document and for the purposes of these standards, we suggest the following working definitions. These have no formal status but may be useful conceptually when considering specialist HIV services.
- A specialist HIV treatment and care clinic provides outpatient care for people with HIV, whether as part of a specialist HIV centre or in a more generic care environment with links to a specialist HIV centre, and has established links with key clinical and support services.
  - A specialist HIV centre provides dedicated and multidisciplinary inpatient, outpatient and 24-hour emergency care led by appropriate HIV specialists and supported by doctors in training. The centre should have established links with other key clinical and support services integral to complete patient care, which would include provision of emergency medical inpatient care by physicians accredited in general medicine.
  - A specialist in HIV is a trained clinician with extensive experience and competence in the medical management of patients with HIV and all other aspects of HIV patient care.
  - In accordance with clinical governance requirements, all physicians involved with HIV care should participate in continuing professional development appropriate to their level and type of involvement in care.
- 69 It is inevitable that there will always be some physicians who are more expert or experienced than others. In principle, any physician with adequate training and experience can provide HIV care, as long as they deliver it according to these recommended standards and the associated professional guidelines. But as with other areas of medical care, if a physician knows they lack the skill or experience to manage a particular patient or condition, they should seek advice from a colleague with greater expertise and experience and they should always have access to someone to ask. Service networks, of which all such clinicians should be a part, play an important role in this regard.
- 70 It is worth noting that there are other types of 'HIV specialist' outside the medical profession. Too numerous to list, these range from group work facilitators with gay men to social workers with HIV-positive African families, from psychologists supporting adjustment to HIV diagnosis to nurses providing palliative care for those with terminal HIV disease. Integral to all of these is 'specialism' in understanding and meeting the particular needs of the often marginalised communities affected by HIV and its associated stigma. Like their medical counterparts, non-

medical HIV specialists should also have had relevant experience and training in the management of HIV infection.

## Standards for England

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- 71 The standards have been funded and developed for application to services in England. However, it is hoped they will prove relevant and useful in other parts of the UK.
- 72 In Scotland, the Scottish HIV and AIDS Group (SHIVAG) which reports to the Bicollegiate Committee for standards of the Royal College of Physicians of Edinburgh and the Royal College of Physicians and Surgeons of Glasgow, has developed a set of standards in the form of a short list of key measurable indicators for antenatal and specialist HIV care. The Welsh Assembly is conducting a review of sexual health services including the need for the development of standards for HIV services in Wales. No standards for HIV services have been developed specifically for Northern Ireland.

## Links to other government initiatives

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- 73 Tackling health inequalities is a key plank in the government's health and modernisation agendas. There are striking health and social inequalities that can both contribute to, and be compounded by, sexual ill-health and HIV infection. By providing a framework for facilitating equity of access and quality of care for people with HIV, these standards should help the NHS and partners work towards reducing health inequalities.
- 74 The Department of Health's agenda for quality improvement, as set out in *A first class service*, identifies clinical governance as the mechanism for ensuring that national standards are reflected in the local delivery of services. The standards will rely on clinical governance for their implementation.
- 75 In seeking to empower HIV service users to take control of their own health and care, these standards link closely to the government's plan for *The expert patient: a new approach to chronic disease management for the 21st century*. There is a degree of commonality of purpose, combined with principles and themes comparable to those underpinning these standards, which warrant drawing on this plan where relevant to HIV care, even though HIV is not explicitly included. In advocating the involvement of service users in service networks, the standards should take account of arrangements for *Involving patients and the public in healthcare*.
- 76 As HIV is a complex disease with a wide range of medical and social implications, implementation of quality standards for its prevention, treatment and care should be undertaken alongside that of national standards for related areas of healthcare including *The NHS cancer plan*, *Getting ahead of the curve: a strategy for combating infectious diseases*, *the National service framework for mental health*, the forthcoming national service frameworks for children's services and for long term medical conditions, and the *Hepatitis C strategy for England*. Further existing national standards and guidance are referred to in other sections of this document, where they are particularly relevant.

## How to achieve and maintain standards

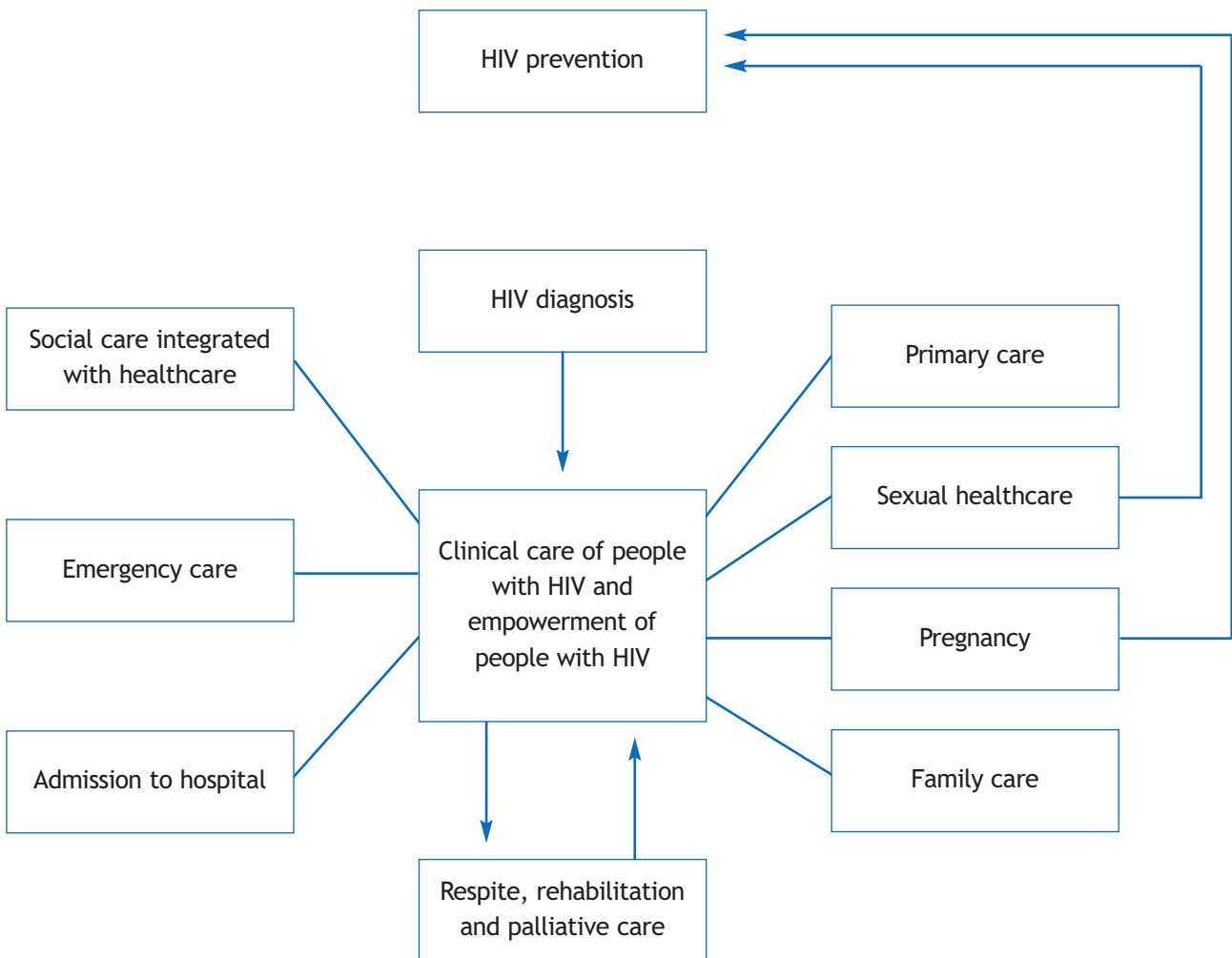
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- 77 PCTs hold commissioning responsibility for local HIV prevention, treatment and care services. PCTs are therefore ideally placed to use these standards in commissioning and planning. Mechanisms should be developed to establish and monitor:
- clear and updated assessment of HIV-related need
  - effective operation of a multi-agency planning group to develop, implement and evaluate an HIV prevention, treatment and care programme reflective of local need
  - clear protocols to cover the roles and responsibilities of all services with a contribution to make towards achieving these standards
  - continuing professional education and development
  - appropriate and transparent arrangements for the commissioning of all work
  - appropriate capacity and resources to achieve and maintain standards
  - arrangements for multidisciplinary audit to review implementation of the standards across the HIV service network and assess the impact of the programme.
- 78 The combination of levels of local HIV prevalence and the historical legacy of service delivery will be likely to result in most PCTs deciding to operate in consortia, thereby maximising the commissioning power whilst minimising the financial risk to each PCT. Such arrangements may also be considered advantageous to the operation of these standards, especially as HIV service networks will usually cover an area equivalent to more than one PCT.
- 79 Guidance and support for PCTs from both the DoH and strategic health authorities (SHAs) can help with the adoption of these standards. The Department of Health's *Effective commissioning of sexual health and HIV services: a sexual health and HIV commissioning toolkit for primary care trusts and local authorities* provides models for best practice in commissioning that should facilitate the implementation of these standards through networks. SHAs should find the standards a useful tool when supporting network development and managing the performance of PCTs, NHS trusts and Workforce Development Confederations.
- 80 Implementation of these recommended standards is likely to benefit, in many areas, from a phased approach over a period lasting longer than a single year. It would be helpful to reach agreement locally between service commissioners, providers and users on priorities and milestones for this process.

## Chapter 2: The recommended standards

This chapter is in two sections. The first presents a standard for the development of managed service networks and delivery of care through this mechanism. Networks provide a way in which service providers, commissioners and users can work together to plan and deliver services to meet standards of care. (The project which developed these standards is undertaking further work on the development of managed service networks for HIV, which will result in a separate publication.)

The second section presents a set of 12 standards for prevention, treatment and care following the care pathway. However, it must be stressed that the 'pathway' in HIV will not be a linear progression from Standard 1 to Standard 12. Individuals with HIV may need any of the services covered by the standards, in almost any order, so the sequence selected is, to a degree, arbitrary. The diagram below suggests an alternative view.



## Format of the recommended standards

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The standards all have the same format, containing the following sections.

### **Aim**

The intended outcome of the standard for people with, or at risk of, HIV.

### **Standard**

What the NHS should do and/or what people with HIV should have access to, in order to achieve that outcome.

### **Rationale**

What the needs are for the standard and which responses are known, or likely, to be effective.

### **Key interventions**

The most important interventions recommended to meet this standard. These are all based on expert consensus from the project's advisory group and are supported by published evidence where available.

### **Implications for service planning**

The action recommended from the NHS and partner agencies, such as local authorities and voluntary sector providers. The NHS in this context encompasses all relevant commissioning and provider bodies, including PCTs and hospital trusts. This section should also be relevant to SHAs, with their performance management and capacity building roles.

### **Guidance on practice**

Relevant national guidance and regulatory documents, such as those from the DoH, royal colleges and other expert bodies. Some standards also include in this section recommendations for practice put together by the experts on the advisory group during the development of the standards.

### **Suggested audit indicators**

Ways to assess whether the standards have been achieved. This section suggests indicators (what can be measured), rather than targets (what should be achieved). Target-setting will need to be done locally, and these indicators should be useful for that process as well as for monitoring performance over time. They are presented as suggestions, but other relevant indicators may be identified locally.

## Managed HIV service networks

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### Aim

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To deliver excellence and equity of treatment and care for all people with HIV, along the entire care pathway and across defined geographical areas, by coordinating service provision within managed networks.

### Standard

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All people with HIV should have access to services which operate within a managed service network in order to achieve the best possible treatment and care for individuals as close as possible to where they live.

### Rationale

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- 1 HIV is a complex clinical condition, with significant impact on the needs of people with HIV for care, support, and treatments tailored to changing developments in their condition over time. It will be unlikely that all of an individual's needs can be met from any single service working in isolation over their lifetime.
- 2 There is a need to balance and coordinate different sorts of provision, across NHS primary secondary and tertiary care, local authority social care, and voluntary sector services, and between services delivered as locally as possible and some more specialist treatment which may need to be provided at a greater distance.
- 3 The changing epidemiology of HIV within the UK means that an increasing number of individuals may need to access services in any area of the country, including areas where there has historically been low prevalence of HIV. The quality of the network of services should be equally good, wherever they are.
- 4 A number of individuals with late diagnosis of their HIV status may have complex and immediate treatment needs. Clear referral pathways and protocols are recommended for these individuals to ensure rapid access to appropriate treatments.
- 5 Network arrangements allow for coordinated and planned provision of expertise from differing services across a network area, to support the multiple and changing needs of people with specific conditions, such as HIV. They enable parts of the country with very different levels of prevalence to organise services in a way appropriate to local conditions, while facilitating access to the same quality of treatment and care.
- 6 Managed service networks have been defined as: 'linked groups of service users, professionals and organisations convened by commissioners – spanning NHS primary, secondary, and tertiary care, the voluntary sector, and social care – which work in a coordinated manner unconstrained by existing professional and organisational boundaries in order to ensure the equitable provision of high quality and effective services throughout the network area'.

(Scottish Executive (1999) NHS MEL [1999] 10: *Introduction of managed clinical networks within the NHS in Scotland*. Edinburgh: Scottish Executive. Available at [www.show.scot.nhs.uk](http://www.show.scot.nhs.uk))

- 7 Other specialist services are increasingly operating through network arrangements to ensure the right concentration of knowledge and expertise is made available to individuals at every stage in their care pathway.
- 8 Networks are an increasingly common model in easing the pathway between acute-based hospital care and community-based primary and social care.
- 9 Networks need to be multidisciplinary, multi-agency bodies, and can provide a mechanism for:
  - service funding and budgeting
  - planning and implementing service developments
  - quality management and audit
  - professional education.
- 10 Networks take time to set up and are likely to continue to evolve. An assessment of cancer networks in England and Wales found their development to have been slow and uneven, with only one (out of those visited) which seemed to be working as a truly joint enterprise. This network had set up a management board early on, involving health authority and trust chief executives (or director level representatives), and employed a network manager. It had made an active effort to involve the public in network decisions, published strategy statements, developed common standards, and audited and published the results for the most common cancers. The assessment report acknowledged that working in networks required a significant change from traditional practice (from 'vertical' to 'horizontal' relationships), and recognised the need for GPs and patients to become more involved in networks.
- 11 Key principles which support the establishment of networks, drawn from the work of Mark Ebers and adapted by Kate French and Breda Flaherty (in *Developing service networks for HIV acute care in London*), include the following.
  - *Establishing a valid rationale for networking*: organisations and individuals must foresee clear gains from collaboration, eg:
    - to achieve better output or outcomes
    - to achieve fast learning, especially in rapidly-changing fields
    - to reduce risk and improve stability, especially where multiple organisations are shouldering innovation and change
    - to pursue common or mutually beneficial goals.
  - *Good network partner decisions*: individual participants in networks must be convinced of mutual trustworthiness and the potential to share strategic goals.
  - *Network design*: network building is an on-going task as relationships within the network will repeatedly undergo changes which mean re-evaluation.
  - *Coordinating mechanisms*: leadership mechanisms must build collaboration, encompass joint decision-making processes and shared information systems, and be perceived by all parties as valid.
  - *Establishing useful connections cross-network*, eg:
    - *resources and activity links* that lead to interdependence

- *information links* to influence knowledge/perceptions and guide decisions and actions
- *shared expectations* to influence perceptions of risk and opportunity, fairness and trust.

### Key interventions

- Commissioning HIV services within managed service networks, across health and social care organisations, is a way to help put networks in place which are configured to meet local need.
- An HIV network is likely to work most effectively if it covers an area based on local epidemiology and trends in treatment, care and support, taking into account current service configuration and factors such as transport. Most or all networks will probably cover an area encompassed by two or more PCTs, and commissioning can be facilitated through consortium arrangements.
- Networks work best where there are high degrees of ownership from those involved. This can be encouraged by collaborative working between commissioners and providers to agree on an individual to lead the network (for example a lead clinician), local priorities and network coordinating mechanisms which have strong local support.
- The active participation of all healthcare workers and other professionals offering HIV services in a network arrangement, with a duty to be clear about their own role and responsibilities within the network, can help develop effective care pathways for service users in the network area, and help meet their own continuing professional development needs. Such arrangements should include those in statutory, voluntary and self-help organisations.

### Implications for service planning

- 12 PCT commissioners should work together, in collaboration with SHAs, service providers and service users, to designate an HIV network area based on local epidemiology and trends in treatment and care. This process should also take into account other factors influencing the shape and size of networks such as current service configuration and transport links. Within parameters developed by commissioners, it is recommended that work be undertaken by NHS trusts and other providers to define referral pathways within the network and agree on the organisational changes required to implement them.
- 13 PCTs should agree arrangements for commissioning across an HIV network larger than their individual boundaries. Consortium and lead commissioning arrangements outlined in the Department of Health's toolkit for PCTs and local authorities, *Effective commissioning of sexual health and HIV services*, may be a useful way of organising PCT involvement.



- 14 PCTs and local authorities should work in partnership, using flexibilities set out in Section 31 of the Health Act 1999, to move towards integrated commissioning and provision of HIV health and social care across the network. It is recommended that commissioners should:
- take account of local needs assessment, including the 2002 baseline exercise commissioned by the DoH
  - assess the effectiveness and value for money of currently commissioned services
  - identify gaps, strengths and weaknesses at local level among the range of organisations within the network
  - facilitate equity of care for people with HIV whatever their access point within the network
  - allocate resources for the development and functioning of the network
  - be transparent and clear about whether funding is allocated directly to providers or via the network.
- 15 The NHS, local authorities and partner agencies are advised to set up and ensure the effective operation of a multi-agency planning group to develop, implement and evaluate the HIV network, involving health and social care services from the statutory and voluntary sectors, and service users. (See also Standard 6.) They should:
- facilitate network development in line with the key principles which support the establishment of networks (see above, para 11)
  - agree lead arrangements for network coordination and management
  - set up systems to ensure service users are integrally involved in network arrangements.
- 16 Networks should look at ways to engage all services providing health or social care for people with HIV, including those whose primary function is more generic, such as primary healthcare or A&E, as well as specialists in related areas of care, such as obstetrics or haemophilia.

### Guidance on practice

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- 17 The Department of Health's commissioning toolkit provides guidance on commissioning HIV services through managed service networks. (Department of Health (2003) *Effective commissioning of sexual health and HIV services: a sexual health and HIV commissioning toolkit for primary care trusts and local authorities*. London: Department of Health. Available at [www.doh.gov.uk](http://www.doh.gov.uk))
- 18 Principles for involving people with HIV in organisations providing HIV services have been developed by the Greater Involvement of Positive People (GRIPP) working group. (Greater Involvement of Positive People working group of the Pan London HIV/AIDS Providers Consortium (2000). *Basic principles of positive people's involvement in HIV/AIDS service organisations*. Available on request from [consort@consort.demon.co.uk](mailto:consort@consort.demon.co.uk))

### Suggested audit indicators

- Commissioning established through a managed service network, using a Network Board for commissioning, clinical governance or other coordinating mechanisms.
- All organisations delivering health and social care services for people with HIV to be part of a managed service network.
- Each network established in line with the good principles framework above (para 11).
- As the network develops, a network lead (or leads) appointed.
- Local priorities established for the network, resource allocation across the network in line with local priorities and HIV service standards, and audit systems in place for services across the network.
- Care pathway routes identified and priorities in the implementation of the standards at each point of the pathway agreed within the network, with accountability clearly defined.
- Regular survey of service users' perceptions and experience across the network.

For further reading see page 94

## HIV prevention

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### Aim

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To minimise the number of people who become infected with HIV, by integrating HIV prevention work across health service and community settings, and with HIV treatment and care services.

### Standard 1

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A comprehensive evidence-based HIV prevention programme, integrated with other initiatives to promote sexual health and reduce transmission of blood borne viruses, should complement and involve HIV treatment and care services.

### Rationale

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- 1 The prevention of HIV and the treatment and care of those infected are inextricably linked. Activities overlap, and continuity of service provision is needed (eg for those using prevention services who discover they are HIV-positive). A recommended standard on prevention is included in this document to encourage the planning, provision and evaluation of HIV prevention in coordination with that of the treatment and care services covered by the rest of the standards. Much work has been undertaken elsewhere to provide evidence and guidance on HIV prevention (see Guidance on practice and Appendix A) and this standard could not possibly be comprehensive. It aims merely to set a framework for prevention, as a context for the treatment and care of people with HIV.
- 2 The number of people diagnosed with HIV each year in the UK has risen steadily since 1998. While some have been infected but undiagnosed for years, significant numbers of new infections are still occurring in all age groups particularly among men who have sex with men.
- 3 HIV infection diagnosed in the UK principally results from unprotected sex between an uninfected and an infected person. The two primary transmission routes are sex between men (mostly unprotected anal intercourse, although an estimated 1 to 3 per cent of cases result from oral sex), and sex between men and women (mostly acquired in high prevalence countries, principally in Africa, although recent evidence suggests an increase in transmission within the UK, where one partner has previously acquired HIV overseas). There is a small amount of sexual transmission between men and women who have no links to the epidemic in Africa or other identified risk factors. Individuals can prevent sexual transmission of HIV by practising safer sex, including condom use.
- 4 Transmission through the sharing of drug injecting equipment continues at a relatively low level, but evidence of an increase in sharing indicates the potential for a rapid rise in infections among injecting drug users. Individuals can prevent transmission by avoiding injecting, and never sharing injecting equipment or any equipment for preparing drugs. Where access to injecting equipment is limited, such as in prison, disinfecting equipment with bleach can reduce risk, although this is less effective than using clean equipment. Needle and syringe exchange schemes have been shown to reduce rates of sharing among injecting drug users. Methadone prescribing as a substitute for heroin can help some drug users to stop injecting.

- 5 Transmission also occurs from infected mothers to their children before, during or after birth. Although the number of pregnant women with HIV has been rising, interventions have reduced the proportion of them passing the infection on to their babies. (This aspect of HIV prevention is addressed in Standard 8.)
- 6 *The national strategy for sexual health and HIV* proposes a 25 per cent reduction in the number of newly acquired HIV infections by the end of 2007. To achieve this, there needs to be continuing development of an HIV and STI-educated, empowered and equipped population with access to clear, culturally appropriate, accurate and credible information and quality services (see Guidance on practice).
- 7 All risk behaviours should be addressed, along with the factors which may facilitate them, paying particular attention to work with:
- people with HIV to minimise the potential for onward HIV transmission (see Standard 7)
  - people identified as having elevated levels of risk, such as gay men who have unprotected sex, people diagnosed with other STIs, people who frequently visit countries with high HIV prevalence, people who are part of communities in the UK from high prevalence countries, people who test HIV negative after reporting high risk sexual activity, sex workers, injecting drug users and those in prison
  - young people, including those who are socially excluded, in liaison with schools, educational agencies, youth groups, and other agencies.
- 8 Systematic reviews of the evidence suggest that interventions with men who have sex with men are more likely to be effective if they are:
- placed within the broader context of men's lives, addressing the range of factors which influence risk at both the personal level (eg knowledge, skills) and the structural level (eg discrimination towards gay men, gay community norms towards condoms)
  - tailored and targeted to specific sub-populations of men who have sex with men, for instance black gay men and working class gay men
  - multi-component (using small group work), focusing on risk reduction, sexual negotiation and communication skills training and rehearsal (eg through role-play or identifying 'triggers').
- There is some evidence from reviews that interventions delivered at the community level (particularly peer-led) can be effective in influencing the sexual risk behaviours of commercial sex workers.
- 9 There is some evidence that HIV counselling and testing can influence sexual risk behaviour in some population groups, especially after a positive result. However, the effects of receiving a negative result are not clear – some suggest it may lead to a false sense of security, perhaps increasing risky behaviour.
- 10 STIs, particularly gonorrhoea and genital ulcer disease, in either partner can facilitate the transmission of HIV. STI prevention, diagnosis, treatment and care need to be part of a comprehensive HIV prevention programme. (See Standard 7 for STI screening for people with HIV.)

- 11 Post-exposure prophylaxis after non-occupational exposure (NONOPEP) is being increasingly used and the evidence for effectiveness is from comparison with occupational exposure reduction when PEP is promptly used. It is not known within what time period it has to be given to be effective, and this should be taken into account when developing protocols or considering individual requests for PEP after sexual or drug injecting exposure.
- 12 HIV remains a stigmatised condition and primarily affects communities which are socially excluded and/or stigmatised. Any measure to reduce social exclusion, stigma or discrimination, especially in relation to these communities, is likely to help reduce rates of HIV transmission.
- 13 Balancing the needs of people with HIV and those who are not infected can present ethical challenges for healthcare workers involved in HIV prevention, for example in relation to disclosure of HIV status to sexual partners. An underlying principle is that the promotion of one person's health should not be at the expense of another's.
- 14 The screening of donated blood and body tissue, and the treatment of blood products, have virtually eliminated the risk of HIV transmission through these routes in the UK. Occupational transmission from people with HIV to healthcare workers and other professionals is rare, and to date there have been no reported cases of transmission from a healthcare worker to a patient in the UK. Detailed guidance for healthcare workers is in place to keep such transmission to a minimum and to avoid cross infection in medical settings (see Guidance on practice).

### Key interventions

- The number of new infections occurring in the population can be reduced by interventions to inform and support individuals in reducing risk behaviours and by minimising the factors that promote such behaviours, particularly in sub-groups of the population at greatest risk.
- Individuals can reduce their risk of acquiring or transmitting HIV if they practise safer sex and do not share drug injecting equipment.
- The diagnosis, treatment and care of other STIs in populations at risk can reduce the rate of sexual transmission of HIV.
- The provision of clean injecting equipment can reduce rates of sharing, and the prescribing of methadone can reduce rates of injecting, both leading to a reduction in the risk of HIV transmission among injecting drug users.

## Implications for service planning

- 15 The NHS and partner agencies, through a multi-agency planning group, should develop, implement and evaluate a local HIV prevention programme which:
  - is part of a broader sexual health promotion programme
  - links with other key strategies, most particularly the local Teenage Pregnancy Strategy and Action Plan and the local Health Improvement and Modernisation Plan
  - is informed by an up-to-date assessment of local HIV prevention need
  - is transparently commissioned, in line with the Department of Health's *Effective commissioning of sexual health and HIV services: a sexual health and HIV commissioning toolkit for primary care trusts and local authorities*
  - is adequately resourced in a way which reflects priorities identified through needs assessment
  - is developed and delivered with the involvement of target populations
  - is coordinated across primary and secondary healthcare, and community settings
  - is multi-agency and multidisciplinary, linking clinically based, community and education-based initiatives
  - includes work with specific population groups as well as with the general population
  - complements nationally funded and delivered HIV prevention campaigns
  - has protocols governing work undertaken with each population group
  - includes interventions at individual, small group and population level
  - is based on evidence of effectiveness and good practice guidance, as set out in the Department of Health's toolkit, *Effective sexual health promotion* (see Guidance on practice)
  - is focused on achieving conditions such as those set out for gay men by the DoH-funded Community HIV/AIDS Prevention Strategy (CHAPS) (see Guidance on practice) in order to empower people to minimise the risk of HIV transmission
  - is provided by appropriately skilled practitioners with knowledge of the issues and confidence in raising them sensitively with their clients and service users
  - is audited for impact.
  
- 16 SHAs and PCTs should set up arrangements to support the commissioning of those interventions which, for reasons of cost-effectiveness, are to be undertaken across PCT and/or SHA boundaries.
  
- 17 The NHS and partner agencies should facilitate ongoing professional training and development for healthcare and other workers with a role in HIV prevention. This includes the development of understanding and skills to provide culturally competent prevention activities with different population groups, including black and minority ethnic communities.
  
- 18 The NHS should make NONOPEP available for all who need it and develop protocols for provision.
  
- 19 The NHS should make all trusts and healthcare workers aware of existing guidance on preventing occupational exposure and iatrogenic transmission by:
  - adherence to universal precautions and other infection control measures

- provision of PEP for occupational transmission
- ensuring the safety of the blood supply and donated tissue.

## Guidance on practice

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- 20 The Department of Health's sexual health promotion toolkit sets out a planning framework and practical guidance on good practice. (Department of Health (2003) *Effective sexual health promotion: a toolkit for primary care trusts and others working in the field of promoting good sexual health and HIV prevention*. London: Department of Health. Available at [www.doh.gov.uk](http://www.doh.gov.uk)).
- 21 The CHAPS project's national framework for HIV prevention with gay men (Hickson F *et al* (2000) *Making it count: a collaborative planning framework to reduce the incidence of HIV infection during sex between men*. London: Sigma Research. Available at [www.sigmaresearch.org.uk](http://www.sigmaresearch.org.uk)) suggests that sexual transmission between men is reduced if they:
- have control over the sex they have
  - are equipped and competent to negotiate sex
  - are knowledgeable about HIV, its exposure, transmission and prevention, and knowledgeable about STIs
  - are aware of the possible HIV-related consequences of their sexual actions for themselves and their sexual partners
  - are free to choose whether and when to test for HIV
  - are knowledgeable about HIV testing and the meaning of HIV test results
  - have access to quality HIV testing services
  - have maximum control over condom failure
  - are knowledgeable about STIs, and how to prevent them, including their transmission, detection and treatment
  - have access to quality sexual health clinical services.
- 22 Many of these conditions are equally important to all population groups at risk of HIV infection. In addition, there are a number of cultural and religious issues which should be addressed for specific groups, for example, differing sexual practices in specific communities and reproductive rights issues. To address these, all educational materials should be culturally competent, linguistically specific, and developmentally appropriate.
- 23 HIV prevention with African communities should be guided by the following underpinning values set out in the national framework for HIV prevention and care for African communities, due to be published by the Department of Health later in 2003:
- all people have a right to self determination and therefore African communities should be empowered to make their own choices
  - honesty, openness and clarity
  - responses should be sensitive to people's cultures and differences
  - equality in the outcomes achieved by prevention
  - planning of HIV prevention should always involve those intended to benefit from it.

- 24 A comprehensive HIV prevention programme should consist of a range of activities informed by evidence of need and, as far as possible, of effectiveness, and including:
- provision of information, face-to-face support and skills development
  - interventions focusing on attitudes and motivation
  - peer-led interventions and outreach work in community settings
  - free or cheap provision of condoms, lubricants and clean syringes
  - availability of methadone for heroin injectors
  - provision of NONOPEP when appropriate, with clear protocols to ensure equity of access
  - access to HIV testing in a range of settings wherever possible (see Standard 2)
  - partner notification services (see Standard 7).
- 25 There are a number of guidance documents published by the Department of Health on occupational aspects of HIV prevention (all available at [www.doh.gov.uk](http://www.doh.gov.uk)). These include:
- UK Health Departments. *Guidance for clinical health care workers: protection against infection with blood-borne viruses. Recommendations of the Expert Advisory Group on AIDS and the Advisory Group on Hepatitis* (1998)
  - UK Health Departments. *HIV post-exposure prophylaxis: guidance from the UK Chief Medical Officers' Expert Advisory Group on AIDS* (2000)
  - UK Health Departments (2002) *AIDS/HIV infected health care workers: guidance on the management of infected health care workers and patient notification. A consultation paper*. (Replaces the 1998 version. Both are available at [www.doh.gov.uk](http://www.doh.gov.uk))
  - Advisory Committee on the microbiological safety of human tissues and organs used in transplantation. *Guidance on the microbiological safety of human tissues and organs used in transplantation*. (2000).
- 26 The AGUM/MSSVD Clinical Effectiveness Group is developing a guideline on the subject of NONOPEP.



## Suggested audit indicators

### National indicator

- Number of newly acquired HIV infections nationally. (*The national strategy for sexual health and HIV* proposes a 25 per cent reduction by 2007.)

### Local indicators

- Percentage of relevant settings (NHS, other statutory and voluntary) where up-to-date literature on HIV prevention is available.
- Availability of literature in all commonly spoken languages and relevant to different sexes and sexual lifestyles.
- Percentage of GUM clinics, family planning clinics, general practices, voluntary sector and service user organisations where free condoms are available.
- Waiting times for STI diagnosis and treatment in GUM.
- Availability of needle and syringe exchange within each service network.
- Availability of opiate substitute prescribing within each service network.
- Number of sterile needles and syringes dispensed.
- Interventions in place for prevention work with key target groups such as gay men, African communities and people with HIV, based on local epidemiology and evidence of effectiveness where available.

For further reading see page 96

## Early diagnosis of people with HIV

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### Aim

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To enable people with HIV to discover their infection as early as possible, thereby allowing access to appropriate interventions that will promote individual health and reduce the risk of onward transmission.

### Standard 2

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The NHS should develop, implement and monitor strategies to encourage the uptake of testing and reduce the number of people who are unaware of their HIV infection.

### Rationale

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- 1 Many individuals are unaware of their HIV infection. Recent data suggest that HIV is unrecognised in approximately one third of people currently living with HIV in the UK. This proportion will vary according to geographical and socio-economic circumstances. The proportion of heterosexual men and women, including those from minority ethnic groups, who are unaware of their HIV infection is higher than that of gay men or injecting drug users.
- 2 HIV infection may be without symptoms for many years. HIV testing should be routinely considered when risk factors for HIV are identified. When symptomatic disease develops, the symptoms and signs are often non-specific and an underlying HIV infection can easily be missed by both infected individuals and healthcare workers. In addition to well-recognised diseases associated with late stage HIV infection (such as pneumocystis carinii pneumonia, toxoplasmosis and encephalitis), there are certain other clinical scenarios, such as TB, thrombocytopenia, lymphoma and oral candida where HIV testing should be routinely considered (see also Standards 5 and 10).
- 3 Earlier diagnosis and monitoring of asymptomatic infection can assist interventions to prevent progression of immune deficiency leading to symptomatic disease. Earlier diagnosis of symptomatic disease and AIDS can prevent deaths. The proportion of HIV-infected people who are first diagnosed late in the course of their infection is significantly higher among certain groups, such as heterosexuals including those from minority ethnic groups.
- 4 Earlier diagnosis can also allow access to a range of services to help prevent onward transmission, including sexual healthcare, advice on safer sex, partner notification, and specialist antenatal care if needed (see Standards 4 and 9).
- 5 The number of individuals living with HIV will continue to rise for the foreseeable future. It is important to raise awareness of the benefits of testing among the general public, and especially among groups at greater risk. Knowledge of personal HIV status should be encouraged and testing destigmatised. Individuals with multiple risk factors who test negative should be offered advice and support to reduce future risk. Follow-up and retesting of such individuals is desirable.

- 6 People attending GUM clinics are known to be more likely to have HIV infection than the general population, but studies have shown that many are not offered an HIV test, especially if not perceived to be at high risk. In order to achieve the goal outlined in *The National strategy for sexual health and HIV*, GUM clinics should offer an HIV test to all people having their first screening for STIs, and again at later dates according to risk.
- 7 Antenatal screening is an essential requirement to help prevent transmission of HIV from mother to child, by allowing mothers diagnosed with HIV infection to receive appropriate antiretroviral treatment and obstetric management.
- 8 HIV testing is a mandatory requirement for blood, semen and other tissue donors.

### Key interventions

- Increased awareness of rising HIV prevalence, the risk factors, signs and symptoms of HIV, and the benefits of HIV testing, among the general public (especially groups at higher risk) and among healthcare workers, can result in earlier identification of people with HIV.
- Routine offering of HIV testing to individuals with identified risk factors for HIV, clearly identified HIV-related diseases, or certain clinical conditions such as TB, thrombocytopenia, lymphoma or oral candida, can lead to earlier diagnosis of HIV.
- Follow-up and retesting of individuals with multiple risk factors who test negative can lead to early identification of new HIV infections and offer further opportunities for prevention work.
- The routine offer of HIV testing to all individuals requesting a sexual health screening in GUM clinics can increase the uptake of HIV testing among those at higher risk.
- Antenatal screening is an essential requirement to help prevent transmission of HIV from mother to child (see Standard 8).
- The provision of HIV testing in a variety of settings, and according to criteria demonstrated to meet the needs of service users, can increase the uptake of testing (see Guidance on practice).

### Implications for service planning

- 9 The NHS and partner organisations should develop, review, and implement local plans and protocols to:
  - deliver appropriate capacity and resources to achieve increased uptake of HIV testing and to provide ongoing treatment and care for those diagnosed with HIV
  - maximise antenatal HIV testing (see Standard 8)
  - encourage HIV testing in a wide variety of primary and secondary healthcare settings

- increase awareness amongst the general public of the rising prevalence of HIV infection, the risk factors, symptoms and signs, and encourage people to make informed choices and seek knowledge of their HIV status
  - make available patient information in languages and formats appropriate to different population groups
  - include healthcare workers undertaking HIV testing in a service network with clear and rapid referral pathways to treatment and social care providers
  - refer rapidly to a specialist treatment and care clinic after a confirmed positive result (as indicated on two blood samples) – for an appointment within 14 days for those with no symptoms and more promptly for those who are symptomatic
  - prioritise for prevention and monitoring those at risk of acquiring HIV infection but who test negative (see also Standard 1)
  - raise awareness among clinical healthcare workers most likely to come into contact with people with undiagnosed HIV of the rising prevalence, the signs and symptoms, and the risk factors for HIV. These will include:
    - GPs and other clinical members of the practice team
    - dentists
    - opticians
    - pharmacists
    - general medical staff in hospitals
    - A&E staff
    - antenatal clinic staff in hospitals and community settings
    - staff in services for drug users
    - NHS Direct
    - NHS walk-in centres
  - enable healthcare workers undertaking testing to receive appropriate training and regular updating on the medical, psychosocial and public health aspects of HIV.
- 10 The NHS should monitor HIV testing uptake and use its information systems to benchmark both uptake and HIV prevalence in populations with similar socio-economic characteristics.
- 11 The NHS should continue to screen all blood, semen, organ and other tissue donors for HIV and ensure that:
- all those diagnosed HIV-positive are referred into the HIV service network for assessment and ongoing care
  - all those excluded as donors because of risk factors for HIV are encouraged to request an HIV test from a provider of voluntary testing.

### Guidance on practice

- 12 Consensus among experts developing these standards concluded that HIV testing should be:
- voluntary and undertaken with the informed consent of the tested person
  - confidential
  - accompanied by a range of written materials that are culturally competent, linguistically specific, and developmentally appropriate

- accompanied by pre- and post-test discussion appropriate to individual need widely available in both primary and secondary care
- encouraged promptly after risk, with follow up at three months to identify people who may be seroconverting
- geographically accessible and available during appropriate hours
- timely with no longer than seven days between testing and the result availability
- available anonymously (ie without having to give their name) for those who would otherwise be discouraged from undergoing testing
- subject to confirmatory testing of second patient samples for those whose first samples have been reported as giving positive results
- available on other body fluids, such as saliva, for those in whom blood sampling is not possible
- accompanied by rapid referral to medical, counselling and social support for those people found to be positive (within 14 days for those who are asymptomatic, more promptly for those with symptoms).

## Suggested audit indicators

### GUM clinic attenders

- Percentage of individuals requesting a sexual health screen who have also been offered an HIV test, as indicated by documentation in patient records and the quarterly KC60 statutory return of diagnoses made in GUM clinics.
- Percentage of individuals offered HIV testing who accepted and had an HIV test performed, as indicated by an HIV test result in patient records and the quarterly KC60 statutory return of diagnoses made in GUM clinics.

### Antenatal clinic attenders

- Percentage of all antenatal clinic attenders undergoing routine screening blood tests who have been offered an HIV test, as indicated by documentation in patient records.
- Percentage of antenatal clinic attenders offered HIV testing who accepted and had an HIV test performed, as indicated by an HIV test result in patient records.

### Other locations

- Percentage of healthcare settings where appropriate written information about HIV testing is available.
- Percentage of healthcare settings, eg GP surgeries, where HIV testing is undertaken on patient request.
- Percentage of test results received within seven days of blood sample being taken.
- Percentage of initial positive samples which were followed by confirmatory tests.
- Percentage of people with HIV who were seen in a specialist HIV treatment and care clinic within 14 days of receipt of confirmation of seropositivity.

For further reading see page 98

## Empowering people with HIV

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### Aim

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To facilitate the empowerment of people with HIV to have personal control and choice over the management of their HIV and to enable them to experience the best possible quality of life.

### Standard 3

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All care should take place in a partnership between people with HIV and care providers so that there is joint decision-making and support to adopt and maintain a healthy lifestyle. Services should recognise the impact of HIV infection on an individual and the stigma and social exclusion unique to HIV.

### Rationale

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- 1 Users of the NHS and other care services should have choice and control over what happens to them at each step of their care. Empowering people with HIV in their relationship with health and other professionals enables them to maintain control over their lives, build confidence, challenge stigma and be as active partners in their care as they wish to be.
- 2 The Expert Patient Taskforce noted that, although people have needs specific to their individual disease, they also have a core of common requirements, for example:
  - knowing how to recognise and act upon symptoms
  - dealing with acute attacks or exacerbations of the disease
  - making the most effective use of medicines and treatment
  - understanding the implications of professional advice
  - establishing a stable sleep pattern, rest and dealing with fatigue
  - accessing social and other services
  - managing work and the resources of employment services
  - accessing chosen leisure activities
  - developing strategies to deal with the psychological consequences of illness
  - learning to cope with other people's response to their chronic illness.
- 3 HIV infection is a lifelong condition that can be fatal and impacts upon almost every aspect of life. Living with HIV is not easy. Treatment can be complex, medication is indefinite, usually self-administered, and may need a range of lifestyle and diet changes requiring commitment and active involvement. Side-effects can be debilitating and co-infection with other life-threatening conditions that complicate treatment, such as hepatitis C and TB, is not uncommon.
- 4 People who have an understanding of their HIV, and take an active role in managing it, have been shown to be better able to maintain adherence to long-term treatment. This can lead to reduced levels of viral reproduction and a lower probability of developing resistant strains. However, for a range of reasons, a significant proportion of people with HIV do not understand key elements of their care.

- 5 Additionally, a diagnosis of HIV can lead to poor psychological adjustment, including self-blame, denial and fear of disclosure that can create barriers to managing HIV. The continuing stigma and poor public understanding of HIV can create or reinforce a sense of low self-esteem and increase isolation and feelings of depression. Fear of social exclusion can lead to non-disclosure and failure to access appropriate medical and social support services. While the health benefits of active involvement in care are clear, a commitment to the person with HIV having choice and control over what happens to them means that this must be balanced with their autonomy in choosing how they live their life with HIV. The health and social care professional's role is to ensure that choices are informed by an understanding of their risks and consequences.
- 6 The provision of information, education and psychological support that facilitates self-management, including dealing with stigma, is therefore a cornerstone of HIV care. Professionals need to be able to motivate and support people with HIV to manage their own lives, including how to deal with social exclusion, in line with each person's wishes. This can, in turn, help people with HIV to assess their risks and needs, and to act on that assessment.
- 7 Beneficial factors for people with HIV include:
  - a family and social environment that supports the person with HIV in managing their health and social care needs
  - the tools to support self-management, eg affordable healthy food, access to condoms and clean injecting equipment, control over disclosure, and signposting to complementary therapies
  - active involvement in negotiating, agreeing and owning goals
  - the knowledge to understand the consequences of different choices and to enable action.
- 8 In order to ensure optimal support in empowering people with HIV, it will be important that all such work recognises and reflects the diversity of the HIV-positive population. In particular, the specific needs of those from minority ethnic communities should be addressed. Voluntary sector groups working with affected communities, and organisations of HIV-positive people, may have valuable skills and expertise to offer.



### Key interventions

- Culturally appropriate education, information, and peer support can improve knowledge, confidence and psychological wellbeing. This should be multi-lingual where appropriate, tailored to the needs of the individual, and include skills-based approaches.
- Patient-accessed records can facilitate self-care for some people.
- Personal care plans, developed in partnership between themselves and care professionals, can support the empowerment of people with HIV.
- Referral pathways which include services to combat social exclusion, as well as directly to tackle health problems, support the individual's ability to self-manage aspects of their condition.

### Implications for service planning

- 9 The NHS and partner agencies should develop, implement and audit programmes for empowering people to participate in their care and self-manage aspects of their HIV, which:
- provide information about HIV, its treatment and management
  - provide information about the full range of statutory and non-statutory health and social care services available and how to access them (see also Standard 6)
  - provide information about how services work in the UK, targeted in particular at people who have recently moved to the UK
  - support the adoption and maintenance of a healthy lifestyle, and adherence to HIV treatments
  - support people with HIV, including through the provision of dedicated resources and structures, to engage actively with clinicians and other care professionals
  - support clinicians and other care professionals to work in partnership with people with HIV to develop effective care plans and minimise social exclusion
  - support people with HIV in managing disclosure of their condition and coping with stigma and discrimination
  - include the use of new technologies, including the internet
  - are developed and delivered in a manner which recognises the cultural diversity of groups of people living with HIV in the UK.

In some areas of the country, particularly those with low prevalence of HIV, such programmes may best be achieved by the establishment, or maintenance, of one or more posts for staff with specialist HIV skills and knowledge to act as signposts and referral agents. Such posts might be based in statutory or voluntary organisations.

- 10 The NHS and partner agencies should use ongoing training for health and social care professionals and other staff working in HIV services, to promote the attitudes, skills and knowledge they need to adopt person-centred approaches and partnerships in care with people with HIV.

### Guidance on practice

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The report of the government Task Force on the Expert Patient sets out plans for a programme of training and support to help people with long-term conditions take more control of their own health and treatment. HIV is not specifically addressed. (Department of Health (2001) *The expert patient: a new approach to chronic disease management in the 21st century*. London: Department of Health. Available at [www.doh.gov.uk](http://www.doh.gov.uk))

#### Suggested audit indicators

- Percentage of services for people with HIV (statutory and voluntary) which provide literature on HIV treatment.
- Percentage of services for people with HIV (statutory and voluntary) which provide information about the full range of health and social care services available (statutory, voluntary and run by people with HIV).
- Literature for people with HIV available in all commonly spoken languages and relevant to different sexes, sexualities, minority ethnic groups and new immigrants.
- Development and implementation of clear referral pathways from HIV treatment and care clinics to other agencies that help combat social exclusion.
- Inclusion of service users in local HIV service networks.
- Involvement of service users in development of their own care plans, as documented in their treatment clinic and social care notes.

For further reading see page 98

## Clinical care of people with HIV

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### Aim

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To maintain the highest possible quality of life for people with HIV and to minimise their risk of long-term complications due to disease or treatment.

### Standard 4

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All people with HIV should have access to comprehensive specialist HIV treatment and care services and to a full range of supporting services and medical specialties. All these services should be available irrespective of the site of care.

### Rationale

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- 1 The diagnosis of HIV infection usually has a profound effect on an individual. They now have a lifelong condition and may no longer see themselves as healthy. Major adjustments to their lifestyle may be required in order to remain well and keep the infection under control. Sexual and other relationships may change. To achieve better health usually means being involved in an integrated, specialist outpatient service.
- 2 The decline in AIDS cases and HIV-related deaths since the introduction of effective combination ART in the mid-1990s along with a wealth of other evidence shows that HIV is now a treatable long-term condition. However, to maintain a high level of health requires substantial effort on the part of the person with HIV and a high level of expertise and commitment from the healthcare workers whom they see. In order to stay healthy, the regular monitoring of symptoms, CD4 count and viral load will be necessary. People with HIV may also need long-term medication.
- 3 People with HIV continue to be at increased risk of health problems even when on therapy or with a high CD4 count, and the side effects of therapy can lead to new health problems such as metabolic disorders, hepatitis or changes in body shape. Therefore, a structured outpatient programme is required to pre-empt and prevent problems, maintain optimum HIV control and react to new or unexpected problems. Such outpatient care should be provided by healthcare workers who participate in continuing professional development and working with continuously updated protocols and guidelines.
- 4 The range of possible health problems for people with HIV is wide with some conditions requiring care in conjunction with non-HIV-specific specialties such as ophthalmology, oncology, dermatology, neurology, mental health, dentistry and others. Such expertise may only be based in a few regional centres. Access to such expertise is vital to an integrated and comprehensive care package.

- 5 Coordination of outpatient care with other healthcare and support for people with HIV can improve the overall quality of care. This includes regular two-way communication between primary healthcare and HIV specialist outpatient services, and integrated assessment and planning of social care along with healthcare (see also Standards 5 and 6).
- 6 Psychological support can help people with HIV adhere to treatment and make best use of healthcare services. There is increasing evidence that psychological interventions to enhance stress management can be followed by reductions in HIV disease progression. People with HIV also need information and specialist advice on the nature and implications of their treatment, in order to enable them to take an active role in managing their HIV and maintaining their health. This includes information about the risk of interactions between HAART and recreational drugs or complementary therapies (see also Standard 3).
- 7 It has been found both that HIV infection is more frequent among people with mental health problems, and that mental health problems are more frequent among people with HIV. Coordination between specialist treatment services and community mental health teams is recommended, and GPs often have a role to play in enabling this (see Standard 5).
- 8 Provision of differing models of care may be necessary to meet the various needs of patient groups such as black and minority ethnic groups, drug users, women and gay men.

### Key interventions

- Monitoring the development of symptoms, CD4 count and viral load in people with asymptomatic HIV leading to the introduction of therapy at a time before significant illness has developed, enables people with HIV to live a longer, healthier life.
- ART following the BHIVA national guidelines usually leads to a fall in viral load, improvement in CD4 count, remission of any ill health and reduction in mortality.
- Regular monitoring of therapy with rapid access to viral load testing, CD4 counts, resistance testing and therapeutic drug monitoring leads to better virological control and reduction in treatment failures.
- Adherence support for people with HIV before commencing, and while taking, ART reduces treatment failure and should be a key part of each individual's care plan.
- Access to specialist care for certain complications of HIV, such as cytomegalovirus (CMV) retinitis and lymphoma, improves the disease prognosis.
- Care within a multi-professional setting which includes attention to social, psychological, financial and legal issues leads to improved outcomes. Complementary therapies may also improve wellbeing.
- Regular review of people with HIV by healthcare workers experienced in HIV care improves the quality of clinical care and can reduce adverse effects of therapy. This care usually involves a consultant, specialist nurse, dietician and pharmacist and close liaison with the GP.
- Providing good access to local care is necessary in order to diminish the impact of HIV on some of the poorest and most deprived members of the population. However, there are occasions when some people with HIV will have to travel for specific therapy.

### Implications for service planning

- 9 The NHS and partner agencies should review provision of HIV services in order to identify any deficiencies. This would be done through HIV service networks, including statutory and voluntary sector organisations.
- 10 The NHS should develop and implement protocols for specialist outpatient care, utilising national, regional and local guidelines. These should be monitored by regular audit that takes account of the differing needs and conditions of specific patient groups and sites of care. Patient satisfaction is a key indicator of success. All people with HIV should be able to receive good quality local care with:
  - standard HIV monitoring tests as recommended by BHIVA (including viral load, CD4 count,

- resistance testing, therapeutic drug monitoring)
  - access to specialist pharmacy advice
  - rapid access with clear referral pathways to specialist services experienced in HIV (such as salvage therapy and lipodystrophy clinics; specialists in ophthalmology, oncology, dermatology, hepatology, neurology, palliative care, and mental health), if not available locally
  - access to a range of clinical trials for all people with HIV irrespective of their main site of care
  - provision of information about appropriate complementary care providers.
- 11 The NHS should enable all healthcare workers involved in providing outpatient care for people with HIV to receive appropriate and ongoing training in order that they remain skilled in HIV care.

### Guidance on practice

- 12 The BHIVA guidelines for the treatment of HIV infected adults with ART provide a standard for clinical care which is regularly reviewed and updated. (BHIVA Writing Committee on behalf of the BHIVA Executive Committee (2003) British HIV Association (BHIVA) guidelines for the treatment of HIV-infected adults with antiretroviral therapy. *HIV Medicine* 4 (suppl 1): 1-41. Available at [www.bhiva.org](http://www.bhiva.org) – replaces guidelines issued in 2001).
- 13 BHIVA and the MSSVD are producing guidelines on provision of adherence support to individuals receiving ART. (Shortly to be available at [www.aidsmap.org](http://www.aidsmap.org) or [www.bhiva.org](http://www.bhiva.org).)

### Suggested audit indicators

- Percentage of patients who meet the BHIVA guideline criteria for ART who are offered such therapy, as clearly documented in the case notes.
- Percentage of patients who have a regular CD4 count and viral load test.
- Participation of HIV treatment and care clinics in the BHIVA national audits and provision of the means for them to do so.
- Percentage of patients with newly diagnosed lymphoma or CMV retinitis who see a recognised specialist in HIV oncology or HIV eye disease within one week.
- Percentage of patients whose case notes contain recent information about, and a record of action on, social, psychological, financial and immigration issues as necessary.
- Percentage of doctors, nurses and health advisers who undertake the minimum continuing professional development required by their professional body.

For further reading see page 99

## Primary healthcare for people with HIV

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### Aim

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To maximise the quality of life and general health of people with HIV (including those undiagnosed) through the provision of good quality primary care encompassing prevention, diagnosis, treatment and care.

### Standard 5

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People with HIV should have access to good quality primary healthcare provided by local networks, that are sensitive to the needs of those living with HIV.

### Rationale

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- 1 Primary healthcare teams and workers have a role to play in HIV prevention and the diagnosis, continuing primary care, and palliative care of HIV-positive individuals, their families and others close to them. The rest of the standards are relevant for primary care, but Standard 5 focuses on this setting. Primary healthcare is provided in a range of different settings by different service providers. The focus in this standard is primarily on general medical and dental teams.
- 2 Almost a third of all people with HIV infection remain undiagnosed. HIV diagnosis at a symptomatic stage of disease occurs among two-thirds of those who acquire their infection through heterosexual sex, and one-third of those who acquire it through sex between men. In England, late diagnosis is now the most important reason for continuing mortality among people with HIV. People with undiagnosed HIV seek help in a range of health settings, including primary care, where their HIV symptoms may not be recognised and the opportunity for diagnosis is missed.
- 3 Healthcare workers in primary care should be aware that they may encounter patients with undiagnosed HIV and must understand the benefits of testing. They need to have the skills to identify signs, symptoms and risk factors for HIV in order to encourage more testing for HIV, resulting in earlier diagnosis (see also Standard 2 and Standard 8).
- 4 Misinformation persists among GPs and the public about the insurance implications of HIV testing, which may present a barrier to testing in this setting. The policy of the Association of British Insurers (ABI) is that a negative HIV test will not affect applications for life or permanent health insurance, and that negative HIV test results should not be included in GP report forms for insurers. The British Medical Association (BMA) advises doctors not to answer questions relating to an applicant's lifestyle on these forms. Applicants must be given the option to see their GP's report before it is sent to the insurance company.

- 5 People with HIV can benefit from being registered with a GP and having access to other primary care practitioners. Specialist HIV treatment and care clinics are often not in a position to meet their patients' non-HIV related healthcare needs, and primary care plays an important role in the general healthcare of people with HIV.
- 6 Some people with HIV fear discrimination or lack of confidentiality in primary care and choose either not to disclose their HIV status or not to use primary care services. Adopting and publicising policies on anti-discrimination and confidentiality within general practice can increase the proportion of patients willing to disclose their status in this setting, thus enabling the provision of better quality primary care and facilitating communication and shared care with specialist clinics.
- 7 Awareness in primary care of local specialist HIV services and explicit pathways for referral, with regular two-way communication between primary and secondary care, can improve the coordination of the care of individuals with HIV. This can be facilitated by the inclusion of primary healthcare workers in HIV service networks.
- 8 The GP has an important role to play in enabling people with HIV to access integrated health and social care services at a local level, in collaboration with both statutory and voluntary agencies. Professional collaboration on patient care pathways can be facilitated by the development of an HIV service network across primary and specialist care.
- 9 Because mental health services have more local catchment areas than HIV treatment and care clinics, the GP and primary healthcare team are often best placed to enable people with HIV to access local mental health services and liaise with community mental health teams.
- 10 Primary care can have a significant role in widening provision of interventions which can prevent HIV, such as condom distribution and methadone prescribing in general practice, or needle exchange and condom sales in pharmacies.
- 11 Timely dental care can help people with HIV to maintain good oral and general health. However, access to general dental care is difficult for some people with HIV. The UK General Dental Council policy is that it is unethical for a dentist to refuse to treat a patient solely on the grounds that the person has a blood borne virus or any other transmittable disease or infection.
- 12 Oral manifestations of HIV infection are common. General dental practitioners can play a role in the early detection of these diseases and hence the underlying HIV infection.
- 13 Like the rest of the general population, all people with HIV are entitled to dental check-ups at regular intervals.



### Key interventions

- Increasing awareness among healthcare workers in primary care of rising HIV prevalence, the signs, symptoms and risk factors for HIV, and the benefits of HIV testing can result in earlier identification of people with HIV.
- Routine consideration of HIV testing for individuals with identified risk factors for HIV, clearly identified HIV-related diseases, or with certain clinical conditions such as TB, thrombocytopenia, lymphoma or oral candida, can lead to earlier diagnosis of HIV (see also Standard 2).
- Access to primary medical and dental care for all people with HIV can enable them to receive comprehensive healthcare which complements their specialist HIV care.
- Adopting and publicising policies on anti-discrimination and confidentiality can increase the proportion of patients willing to disclose their HIV status in general practice, thus improving the quality of care which can be provided in this setting and facilitating professional communication and shared care with specialist clinics.
- Awareness in primary care of local specialist HIV services and explicit referral pathways can enable prompt access to specialist HIV care.
- Regular two-way communication between primary and specialist care, can improve coordination of the care of individuals with HIV (see also Standard 4). This can be facilitated by the inclusion of primary healthcare workers in HIV service networks.

### Implications for service planning

- 14 The NHS and partner agencies should develop, review and implement local arrangements and protocols to ensure that:
- primary healthcare workers most likely to come into contact with people with undiagnosed HIV are aware of the rising prevalence, the signs and symptoms and the risk factors for HIV (see Standard 2)
  - primary healthcare workers receive appropriate and ongoing training in the medical, psychosocial and public health aspects of HIV
  - all people with HIV are able to register with a GP and have access to a dental practitioner
  - primary care services are part of a network with clear and rapid referral pathways to treatment and social care providers
  - all primary healthcare workers who work with people with HIV are involved in the network. This should include those providing primary care to prisoners, asylum seekers and other vulnerable population groups.

- 15 The NHS should encourage primary care settings to be accessible to people with HIV so that they feel able to use services and disclose their HIV status. Measures to achieve this include:
- the adoption, implementation and publicising of policies on anti-discrimination and confidentiality
  - non-judgemental attitudes and cultural competence in healthcare workers who work with different population groups affected by HIV, including those from black and minority ethnic groups and those with different lifestyles
  - the delivery of services according to the Royal College of General Practitioners (RCGP) Sex, Drugs and HIV Task Group's *Minimum standard of care for HIV in general practice* (see Guidance on practice).

### Guidance on practice

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- 16 The RCGP Sex, Drugs and HIV Task Group's *Minimum standard of care for HIV in general practice* provides guidance on the skills and knowledge required by the clinical team and on general and ethical principles for the whole practice. (Royal College of General Practitioners (RCGP) Sex Drugs and HIV Task Group (2003) *Minimum standard of care for HIV in general practice*. Available from Kathleen Dyer, Clinical Network, Royal College of General Practitioners, 14 Princes Gate, Hyde Park, London SW7 1PU. Tel: 020 8778 0354. Email: agc00@dial.pipex.com).
- 17 General Dental Council guidance includes its policy on treating individuals with blood borne viruses, including HIV. (General Dental Council (2001) *Maintaining standards. Guidance to dentists on professional and personal conduct*. Available at [www.gdc-uk.org](http://www.gdc-uk.org)).
- 18 Joint guidelines from the BMA and the ABI advise GPs on how to deal with requests from insurance companies for medical reports. (Association of British Insurers & British Medical Association (2002) *Medical information and insurance. Joint guidelines from the British Medical Association and the Association of British Insurers*. London: British Medical Association. Available at [www.bma.org.uk](http://www.bma.org.uk)). GMC guidance on confidentiality sets out doctors' duties in relation to disclosing patient information to third parties, such as insurance companies. (General Medical Council (2000) *Confidentiality: protecting and providing information*. London: General Medical Council. Available at [www.gmc-uk.org](http://www.gmc-uk.org)).

### Suggested audit indicators

- Percentage of healthcare workers in general practice who are aware of anti-discrimination and confidentiality policies, and who state that their practice implements and publicises these. Suggested monitoring tools – staff surveys.
- Percentage of people with HIV attending specialist HIV treatment and care clinics who have disclosed their HIV status to their GP. Suggested monitoring tool – specialist HIV treatment and care clinic notes.
- Percentage of people with advanced HIV disease who see a dentist every year. Suggested monitoring tool – specialist treatment and care clinic notes.
- Frequency of communication from specialist services to GPs about the care of individual patients with HIV. Suggested monitoring tool – regular network communication audits.

For further reading see page 100

## Social care integrated with healthcare for people with HIV

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### Aim

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To maximise the quality of life and value of clinical interventions for people with HIV, by enabling them, their carers and dependants to access a range of social care services which are provided in coordination with healthcare services.

### Standard 6

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All people with HIV should have access to social care services which are responsive, culturally appropriate and tailored to individual need. All people with HIV requiring multi-agency support should receive integrated health and social care.

### Rationale

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- 1 This document, whose main focus is healthcare, includes a standard on social care in recognition of the inextricable link between social and healthcare needs and the necessity of integrating service provision in response. It would not be possible here to provide a comprehensive standard for social care in all its aspects, and this standard therefore addresses social care primarily as it relates to and supports healthcare.
- 2 People with HIV have a range of needs which impact upon their ability to maintain health. These include needs for both clinical and social care, as well as economic needs.
- 3 Needs are interrelated and priorities vary for each individual. For example, childcare needs, or those arising from poverty or immigration status, may be of greater importance to a mother with HIV than her own treatment needs. Meeting non-clinical, social care needs may therefore be an important pre-requisite for meeting clinical needs. Other social factors such as housing, employment and isolation can have an effect on the health of people with HIV, including their ability to access healthcare services. By getting support to participate in society and improve their economic and social circumstances, people with HIV are better equipped to live healthier lives.
- 4 For many people, improved treatments have meant that HIV has become a manageable part of their lives. Rather than using non-clinical services in an ongoing way, as in the days before HAART, they now tend to access them at times of crisis or significant change such as recent diagnosis, ill or deteriorating health, or for social problems such as housing. Their social care needs may often depend on the state of their physical and mental health, and their capacity to cope with their HIV diagnosis.
- 5 Social care services should be evidence-based, focused on those people and communities in greatest need, and offered within an empowering model which does not foster dependency (see Standard 3).

- 6 Improving coordination between the provision of social care and healthcare can result in a better quality of service for people with HIV and a reduction in inappropriate use of healthcare services. A broad range of providers should be involved in this coordination, including:
  - GPs and primary healthcare teams
  - PCTs including community and clinical nurse specialist teams
  - NHS trusts
  - Social Services departments of local authorities, including hospital social work teams
  - voluntary sector organisations
  - specialist mental health agencies, and other non-HIV agencies where appropriate.
- 7 Integrated arrangements for assessing and meeting social and healthcare needs, including single points of access, can simplify the care pathway, in line with *The NHS Plan*. Full use should be made of the flexibilities within the 1999 Health Act to support the establishment of these arrangements, including pooled budgets. However, at any one time, only a small proportion of people with HIV will have a level of need requiring intensive involvement and integration of care, and resources should be focused on this group.
- 8 Developing integrated care may require institutional and cultural change for healthcare and social care workers. This includes overcoming differences in approach and priority between the agencies involved, as well as working across different geographical and political boundaries. Such change will take time and is likely to be achieved in stages.
- 9 Integrated working can place a strain on organisations, such as local authorities, mental health agencies and voluntary organisations, which need to work across a number of different service networks. This can be eased by collaboration between commissioners and the involvement of providers in the development of networks.

### Key interventions

- Provision of a range of social care services, responsive to local need, can help people with HIV lead healthier lives and improve their use of healthcare services.
- Providing health and social care services for people with HIV in an integrated way, in line with *The NHS Plan*, can improve the effectiveness of both, resulting in better health outcomes.
- Single points of access for the full range of health and social care services, as well as single health and social care assessments of individual need, can improve the integration of service provision for people with HIV.
- Integrated assessment of health and social care needs at the time of hospital discharge can improve the subsequent uptake of services and quality of care (see also Standard 11).

## Implications for service planning

- 10 The NHS, local authorities and partner agencies should set up a multi-agency planning group to develop, implement and evaluate a network of HIV health and social care services. (See also Standard for managed HIV service networks.) This group should:
  - have strong leadership from senior officers in both the NHS and local authorities
  - ensure full, appropriate and adequately resourced involvement in the HIV service network of statutory and voluntary, social and healthcare providers and service users
  - overcome differences in approach and priority within each of the participating organisations in order to meet common goals
  - establish initiatives to support team development across health and social care services, and between statutory and voluntary sector organisations.
  
- 11 To achieve integrated commissioning and resourcing of health and social care, the NHS and local authorities should:
  - undertake a clear and updated assessment of local HIV health and service need
  - make appropriate and transparent arrangements for the commissioning of all health and social care services included in the network
  - commission social care services which are evidence-based, tailored to individual need and delivered within a framework of best practice
  - commission a range of social care to complement clinical services, which should include emotional support, support for use of healthcare services, advice and advocacy, childcare, practical support and support for carers (see Guidance on practice)
  - allocate appropriate resources to commissioned services, making full use of NHS and Social Services budgets, including the AIDS Support Grant
  - make appropriate use of the flexibilities contained within *The NHS Plan* and the Health Act 1999 to establish lead commissioning arrangements, pooled budgets, single assessments, and joint care teams
  - establish incentives to encourage and support the development of integrated care services
  - make training and other support available to enable team members to discharge their role, particularly in low prevalence areas where few staff may have HIV as the principal focus of their work.
  
- 12 To facilitate integrated provision of health and social care, the NHS, local authorities and partner agencies should agree, implement and audit protocols for:
  - a number of single access points to the range of commissioned HIV services, linked to clear referral pathways within the network
  - joint individual needs assessment arrangements for people with HIV, including a single assessment tool used across healthcare, social care and voluntary sector agencies
  - clear internal referral pathways between and within local authority departments, especially Social Services
  - co-location of health and social care facilities wherever possible
  - provision of up-to-date published information (in appropriate languages and media), describing the full range of statutory and non-statutory health and social care services available and how to access them
  - joint care coordination for people in greatest need

- joint monitoring of service uptake to ensure equity of access relative to need.

### Guidance on practice

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- 13 Social care services cover a range of interventions offered by both the statutory and voluntary sectors and by community groups and networks. Services provided can include the following and consensus among those developing these standards suggested that at least two items from each category should be commissioned as a minimum.

Emotional support

- Counselling
- Peer support – one-to-one, groups

Support for use of healthcare services

- Information – treatments, health promotion
- Treatments support
- Complementary therapies

Advice and advocacy

- Advice on housing, immigration, welfare benefits, employment
- Legal advice
- Advocacy support

Child care support for adults

Practical support

- Domiciliary care
- Re-training and back to work
- Other practical support eg transport
- Language and cultural interpretation

Support for carers.

- 14 Guidance on social care for Africans with HIV in the UK will be provided in the national framework for HIV prevention and care for African communities, due to be published in 2003 by the Department of Health.

### Suggested audit indicators

- Availability of literature for people with HIV describing the range of local health and social care services in appropriate languages.
- Percentage of HIV treatment and care clinic case-notes which include documentation of a combined health and social care assessment.
- Percentage of people with HIV discharged after inpatient care who have a planned and documented package of integrated health and social care.
- Establishment and regular meetings of a local multi-agency planning group to develop, implement and evaluate the network of HIV health and social care services.
- Demonstrable participation of Social Services and voluntary organisations in the HIV service network.

For further reading see page 101



## Sexual healthcare for people with HIV

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### Aim

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To improve the sexual health of people with HIV including the promotion of positive sexual health and the reduction of onward transmission of HIV.

### Standard 7

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All people with HIV should receive comprehensive sexual healthcare integrated with their HIV specialist care.

### Rationale

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- 1 Good sexual health is part of overall good health.
- 2 The introduction of HAART and the improved quality of life for individuals with HIV has increased expectations in terms of sexual health for individuals with HIV. Most individuals with HIV remain sexually active.
- 3 There are higher rates of sexual dysfunction and psychosexual morbidity among HIV-positive individuals than within the general population. As well as being indicators of sexual ill-health for individuals with HIV, sexual dysfunction and psychosexual problems are also related to an increased risk of unsafe sex.
- 4 The majority of individuals with HIV are aware of their HIV status and are in regular contact with services. This makes them an important target group for interventions designed to reduce transmission of HIV to people who are not infected. Interventions likely to reduce the risk of transmission include provision of condoms, needle exchange and treatment for STIs. There is also potentially a role for ART in the prevention of onward transmission. (Interventions to reduce transmission from mother to child are addressed in Standard 8.)
- 5 Post-exposure prophylaxis after non-occupational, such as sexual, exposure (NNOPEP) is being increasingly used for the uninfected partners of people known to have HIV (see also Standard 1).
- 6 Unprotected sex between individuals with HIV also presents a risk of re-infection with new or drug resistant strains of HIV. Interventions to prevent transmission are therefore important for maintaining the health of people with HIV as well as those who are not infected.
- 7 HIV-positive individuals face an increased risk of complications from STIs such as hepatitis A, B and C, human papilloma virus (HPV) infection, syphilis and herpes simplex. The presence of other STIs (in either partner) also increases the risk of HIV transmission between sero-discordant partners. The prevention and treatment of other STIs can therefore improve the health of people with HIV and reduce the risk of HIV transmission.

- 8 There has been a significant rise in annual new diagnoses of syphilis, and about a third of these diagnoses are in gay men who also have HIV infection. Annual screening of gay men with HIV for syphilis (or three-monthly in an outbreak situation) is recommended by the MSSVD to address this.
- 9 As their circumstances change over time, the sexual health risks that people with HIV face may also change. They may not spontaneously mention such changes to their healthcare providers, so it is important that the clinical team raise the issue with them on a regular basis in order to assess their need for advice or testing. Clearly, this requires a sensitive approach and judgement as to appropriateness in each case.
- 10 People with HIV need specialist advice and help to deal with other sexual health problems such as the choice of appropriate contraceptive methods bearing in mind the risk of onward HIV transmission, or the decision whether and how to disclose HIV status to a sexual partner.
- 11 Ensuring access to sexual healthcare in, or through, HIV treatment services can increase the proportion of people with HIV who receive such care. The provision of sexual healthcare for people with HIV by health professionals who are aware of their HIV status will result in more appropriate care.
- 12 However, some people with HIV may still prefer not to discuss their sexual health needs with their HIV treatment and care clinic, and for this reason open access to a range of sexual health services should be maintained.

### Key interventions

- Working with people with HIV, to prevent HIV transmission, can reduce re-infection in those who are HIV-positive as well as new infections in those who are HIV-negative.
- The prevention and treatment of other STIs can improve the health of people with HIV and reduce the risk of HIV transmission.
- Facilitating access to sexual healthcare in, or through, HIV treatment and care services can increase the proportion of people with HIV who receive such care and improve the quality of their care.

### Implications for service planning

- 13 The NHS and partner agencies should develop, review and implement local plans and protocols to:
  - facilitate closer collaboration between HIV treatment and care services and sexual health services through the development of explicit care pathways from the former to the latter. These care pathways should include the provision of emergency sexual healthcare for people with HIV, including post-coital contraception, diagnosis and treatment of

symptomatic STIs and provision of NONOPEP for those in sero-discordant relationships, as well as ongoing STI, contraception and sexual dysfunction services and services addressing HIV-specific issues (see Guidance on practice)

- encourage HIV-positive individuals to seek help and advice regarding sexual health problems from their HIV treatment clinic, including support in developing the skills to allow the negotiation of safer sex, disclosure of HIV status and partner notification
- make HIV treatment and care clinics more conducive to good sexual health work through the adoption of systems for ensuring sexual health is part of routine discussions with service users
- enable health and other professionals in HIV treatment and care clinics to receive appropriate and ongoing training in sexual health, including guidance on the legal and ethical framework within which this work should take place
- make community-based prevention activities available for all people with HIV.

- 14 The NHS should facilitate access to sexual healthcare for individuals with HIV by maintaining open access sexual health service provision as well as availability via HIV treatment and care clinics.

### Guidance on practice

- 15 Sexual healthcare should be integrated into the routine clinical practice of HIV treatment clinics, whether provided within the treatment clinic or through referral protocols. This should include:
- ongoing risk assessment within consultations
  - provision of key prevention activities to all individuals with HIV, including cervical cytology, screening for hepatitis A, B and C, immunisation for hepatitis A and B, provision of male condoms, lubricants and female condoms, and specialist prevention advice
  - prompt access to STI screening, treatment and partner notification for all individuals with HIV
  - access to contraceptive care for all HIV-positive women where appropriate
  - availability of NONOPEP for those in sero-discordant relationships according to agreed protocols
  - availability of counselling, for HIV-positive individuals and for couples where one or both partners have HIV, which addresses the specific sexual health issues relevant to HIV. These include preventing HIV transmission, preventing re-infection, the relationship between HAART and HIV transmission, negotiating safer sex, disclosure of HIV status, and dealing with sexual dysfunction
  - availability, at any time after HIV diagnosis, of preconception counselling for all HIV positive women and their partners (see also Standard 8)
  - partner notification of HIV with all individuals with HIV immediately after diagnosis and on an ongoing basis thereafter, in line with guidelines for partner notification in the forthcoming manual for health advising from the Society of Sexual Health Advisers (SSHA), to be published in 2003
  - adherence to MSSVD standards for management (including screening) of syphilis in individuals with HIV. (Nandwani R & Fisher M on behalf of the MSSVD HIV Special Interest Group (2002) *Clinical standards for the screening and management of acquired syphilis in HIV-positive adults*. Available at [www.mssvd.org.uk](http://www.mssvd.org.uk)).

### Suggested audit indicators

- Percentage of HIV treatment clinic service users receiving regular sexual health risk assessments. Suggested monitoring tool – clinic pro formas for regular treatment clinic consultations to include sexual health prompts.
- Percentage of HIV treatment clinic service users aware of the availability and access points to the full range of sexual health services. Suggested monitoring tool – patient surveys.
- Development and implementation by specified dates of care pathways between HIV services and sexual health services.
- Percentage of gay men with HIV attending HIV treatment and care clinic receiving syphilis screening according to MSSVD clinical standards.

For further reading see [page 102](#)

## HIV and pregnancy

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### Aim

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To achieve the best possible outcome for the mental and physical health of pregnant women with HIV, and to minimise the risk of transmission of HIV to their babies.

### Standard 8

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The NHS should develop, implement and monitor policies that seek to empower and support pregnant women with HIV to maximise their health and reduce mother-to-child transmission of HIV.

### Rationale

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- 1 Women form an increasing proportion of those diagnosed each year with HIV, and this is reflected in a rise in HIV amongst antenatal clinic attenders, diagnosed either before or during pregnancy. Diagnosing HIV in pregnancy, or before, brings a number of benefits.
  - Without any interventions, an HIV-positive woman who breastfeeds has a 25 to 35 per cent risk of transmitting HIV to her baby. If the infection is diagnosed, this risk can be reduced to under 1 per cent through the use of ART, elective caesarean section (ECS) and the avoidance of breastfeeding.
  - Receiving an HIV diagnosis also enables a pregnant woman to access care for her own HIV infection, which should be to the same standard as that available to all other newly-diagnosed people with HIV (as set out in the rest of this document).
  - An HIV diagnosis in pregnancy provides an opportunity for a woman to discuss her situation at the earliest opportunity with a professional who is well-informed regarding the implications for her own health, and the health of her unborn baby. If, after discussion, she makes an informed decision to request a termination of pregnancy, this needs to be arranged in the usual way.
  - Diagnosing HIV in a pregnant woman allows for the opportunity to offer testing to her partner and any existing children (see Standards 2, 4 and 9). This can be facilitated by involving partners in the test and result-giving.
- 2 Offering an HIV test to all pregnant women can increase the uptake of testing and therefore the proportion of women whose HIV infection has been diagnosed. DoH guidance recommends that all pregnant women should be offered and recommended an HIV test (see also Standard 2).
- 3 Treatment according to the most up-to-date BHIVA guidelines (see Guidance on practice) can result in the best outcomes for mothers with HIV and their babies. In addition, clinical healthcare workers with little experience in the field may benefit from access to advice and guidance from an expert in the management of pregnant women with HIV.
- 4 To put in place the recommended interventions, HIV-positive women will require input from a specialist midwife, an HIV physician, a paediatrician, and an obstetrician. These should have sufficient specialist knowledge of the issues involved. Designated individuals for a trust, eg a

named obstetrician, paediatrician and midwife may be helpful. The midwife is often the main point of contact for the woman, and is crucial in the liaison between all the teams.

- 5 The majority of pregnant women with HIV in England come from overseas, mostly sub-Saharan Africa. Concerns such as immigration and housing may be uppermost in their minds and knowledge of English absent or limited. Financing formula feed, essential to enable avoidance of breastfeeding, has presented extra difficulties for asylum seekers. However, amended Asylum Support Regulations, in place since 3 March 2003, now allow an additional payment to be made to pregnant women and children who are being supported by the NASS, in respect of assistance towards the cost of milk or infant formula. This payment is £5 per week for babies under one, and £3 per week for pregnant women and children aged between one and three. GPs are also able to prescribe formula feed to asylum seekers and others when they feel it is appropriate. Integrating provision of social care and primary healthcare with specialist healthcare can offer a range of support and practical assistance which may improve service uptake and outcomes.
- 6 Within some populations, there are particular concerns about the use of ECS or avoiding breastfeeding, while the stigma of HIV may result in pregnant women having great difficulty disclosing their HIV status to their partner and other family members. These all act as potential barriers to the use of services and take-up of interventions.
- 7 Movement of women with HIV around the country, and especially dispersal of asylum seekers, means that it is not only the big city centres that will need to care for pregnant women with HIV and their families. Communication between referring and receiving hospitals, and with NASS, is important, to ensure continuity of care in pregnancy when asylum seekers are dispersed.
- 8 A number of women who already know they have HIV, and who may be taking HAART, will become pregnant by choice or by accident or will consider a pregnancy. Clinical healthcare workers in HIV treatment and care clinics need to be aware of the potential harmful affects of particular antiretrovirals in pregnancy and convey this to women with HIV.
- 9 Alternative methods of conception can enable women with HIV to become pregnant without putting their male partner at risk of HIV infection if they are currently uninfected. Likewise, spermwashing can enable men with HIV to father a child while reducing the risk of HIV infection for the mother. In addition, some people with HIV need investigation and treatment for infertility. Clinical healthcare workers in HIV treatment and care clinics should be able to give advice on all of these and their availability. Access to each of these services is currently variable around the country. Standardising their provision nationally, with clear guidance for acceptance and treatment, could enable equity of access for all people with HIV.

### Key interventions

- Offering and recommending an HIV test to all pregnant women, in line with the national antenatal HIV screening programme, can increase the proportion of women with HIV whose infection is diagnosed (see also Standard 2).
- Diagnosing HIV during, or before, pregnancy can enable the offer of interventions to reduce mother to child transmission of HIV, provision of appropriate care for pregnant women with HIV and their babies, access to advice and referral for termination of pregnancy if required, and the opportunity to offer testing to partners and other children.
- Antiretroviral treatment, ECS and avoidance of breastfeeding can reduce from 25-35 per cent to less than 1 per cent the risk of mother to child transmission of HIV.
- Multidisciplinary provision of healthcare, integrated with social care, is likely to improve service uptake and outcomes for pregnant women with HIV and their babies (see also Standard 6).
- Discussion with all people with HIV, soon after diagnosis, of the risks and options for future pregnancy or fatherhood can facilitate conception while reducing the risk of HIV transmission to partners. It can also ensure the most appropriate antiretroviral treatment for women before, during and after conception (see also Standard 7).

### Implications for service planning

- 10 The NHS should continue to support and fund antenatal HIV screening in order to maximise rates of offer, uptake and diagnosis. It should:
  - regularly review protocols, to ensure all pregnant women are offered and recommended an HIV test
  - ensure clinical healthcare workers providing care for pregnant women are aware of the benefits of antenatal HIV testing, and the interventions to reduce mother-to-child transmission, so they can advise all their patients appropriately. These healthcare workers include:
    - obstetricians, midwives and nurses in hospital-based antenatal services
    - community midwives
    - GPs and other members of the primary healthcare team
    - staff in assisted conception services
    - local providers of HIV care involved in the antenatal HIV screening programme
  - enable healthcare workers offering or discussing HIV testing with pregnant women to receive appropriate training and support
  - consider how to adjust services to encourage more male partners to be involved in antenatal HIV testing
  - audit individual uptake of antenatal HIV screening by midwives, GPs and obstetricians
  - monitor outcomes of antenatal HIV screening programmes.

- 11 The NHS and partner agencies should develop, implement and review local arrangements and protocols to:
- enable pregnant women with HIV to receive treatment and care according to national guidelines
  - enable health and social care services to meet the multiple needs, after delivery as well as before, of pregnant women with HIV and their families. These may be very time-consuming and include:
    - support to ensure adequate housing is in place before delivery
    - free formula feed for babies of women with HIV
    - provision of interpreters
  - put in place pathways for prompt referral to termination of pregnancy services for women who, after fully informed discussion, do not wish to continue with their pregnancy
  - offer multi-specialty HIV treatment and antenatal clinics where possible, to avoid the need for multiple appointments
  - facilitate interagency working between HIV specialist, maternity and social care services that does not compromise confidentiality
  - enable clinical healthcare workers providing antenatal and obstetric care to have access to advice from more experienced counterparts within the HIV service network
  - put clear referral pathways in place to more specialist antenatal and obstetric care when needed
  - enable regular and timely communication to take place between the NHS and NASS so that HIV treatment and care and maternity services are informed (and preferably consulted) in advance when pregnant asylum seekers with HIV are to be dispersed from, or to, their care
  - enable non-pregnant women and their partners to have access at any time after diagnosis to preconception counselling, which should include advice about becoming pregnant while on HAART (see also Standard 7)
  - enable all people with HIV to have equal access to assisted conception, with standardised interpretation of the regulations of the Human Fertilisation and Embryology Authority (HFEA) in the light of improved prognosis due to HAART
  - enable all people with HIV to have equal access to spermwashing
  - enable all people with HIV to have equal access to infertility investigation and intervention.
- 12 The NHS and partner agencies should:
- facilitate the involvement of hospital and community-based services providing HIV testing, or care for pregnant women with HIV, in the HIV service network
  - encourage the involvement of GPs and community midwives in HIV testing and care during pregnancy
  - facilitate the involvement of the full range of relevant clinical specialties in the care of pregnant women with HIV
  - designate individuals in each trust from the relevant specialties and disciplines, including obstetrics, paediatrics and midwifery, as HIV experts
  - enable healthcare workers involved in the care of pregnant women with HIV to receive appropriate initial and ongoing training
  - draw national guidelines for the management of HIV in pregnancy to the attention of HIV specialists managing the ongoing treatment and care of women with HIV.



## Guidance on practice

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- 13 There is a large number of relevant documents offering guidance on practice in relation to antenatal screening and prevention of mother-to-child transmission of HIV.
- 14 UK Health Departments (1999) *Targets aimed at reducing the number of children born with HIV: report from an expert group*. London: Department of Health. (Available at [www.doh.gov.uk](http://www.doh.gov.uk)).
- 15 Department of Health (1999) Health Service Circular 1999/183. *Reducing mother to baby transmission of HIV*. London: Department of Health. (Available at [www.doh.gov.uk](http://www.doh.gov.uk)).
- 16 Intercollegiate Working Party (1998) *Reducing mother to child transmission of HIV infection in the United Kingdom. Recommendations of an intercollegiate working party for enhancing voluntary confidential HIV testing in pregnancy*. London: Royal College of Paediatrics and Child Health. (Available at [www.hpa.org.uk](http://www.hpa.org.uk)).
- 17 Lyall EG, Blott M & de Ruiter A et al (2001) British HIV Association. Guidelines for the management of HIV infection in pregnant women and the prevention of mother-to-child transmission. *HIV Medicine* 2: 314-34. (Full version available at [www.bhiva.org](http://www.bhiva.org)).
- 18 Department of Health & Royal College of Midwives (1999) *HIV testing in pregnancy: helping women choose. Information for midwives*. London: Department of Health & Royal College of Midwives. (Available at [www.rcm.org.uk](http://www.rcm.org.uk)).
- 19 Royal College of Midwives (1998) *Position paper 16a. HIV and AIDS*. London: Royal College of Midwives. (Available at [www.rcm.org.uk](http://www.rcm.org.uk)).
- 20 Department of Health Expert Advisory Committees & UK National Screening Committee (2003) *Screening for infectious diseases in pregnancy: standards to support the UK antenatal screening programme*. London: Department of Health. (Available at [www.doh.gov.uk](http://www.doh.gov.uk)).
- 21 Department of Health (2001) *HIV and infant feeding: guidance from the UK Chief Medical Officers' Expert Advisory Group on AIDS*. London: Department of Health. (Available at [www.doh.gov.uk](http://www.doh.gov.uk)).

### Suggested audit indicators

- Percentage of all antenatal clinic attenders undergoing routine screening blood tests who have been offered and recommended an HIV test, as indicated by documentation in patient records.
- Percentage of antenatal clinic attenders who had an HIV test performed, as indicated by an HIV test result in patient records.
- Percentage of HIV-infected pregnant women identified and offered advice and treatment during antenatal care. (This indicator should be in place at local level but is monitored and reported at national level.)
- Percentage of identified women reported to the National Study of HIV in Pregnancy and Childhood via the Royal College of Obstetricians and Gynaecologists (RCOG)'s reporting scheme.
- Percentage of HIV-infected women proceeding with their pregnancy who receive management as outlined in the BHIVA guidelines for pregnancy, unless they specifically object.
- Percentage of HIV-infected mothers assessed, and given the means to enable bottle feeding, including free formula feed and equipment if necessary.
- Percentage of babies of known HIV-infected mothers found to be HIV-negative.
- Percentage of antenatal units with named designated midwife, obstetrician, HIV physician and pharmacist for care of HIV-infected pregnant women.
- Percentage of paediatric units with named designated paediatrician responsible for the follow-up of infants born to HIV-infected mothers.
- Percentage of infants born to HIV-infected mothers who have been reported to the National Study of HIV in Pregnancy and Childhood, via the British Paediatric Surveillance Unit of the Royal College of Paediatrics and Child Health (RCPCH).
- Percentage of doctors, midwives and nurses working in maternity services receiving initial training in diagnosis and management of HIV.
- Frequency of subsequent training and percentage of doctors, midwives and nurses attending.
- Evidence of regular multidisciplinary perinatal management meetings.

For further reading see page 103

## Care of families with HIV

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### Aim

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To enable families affected by HIV to receive coordinated treatment and care services focused on their family needs.

### Standard 9

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Children, their families and carers should have access to specialist adult and paediatric multidisciplinary care including community care and support.

### Rationale

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- 1 This standard addresses the needs of adults and children living together. It is intended to provide a context for standards in the rest of this document on the treatment and care of adults (see especially Standards 7 and 8) and standards available elsewhere for the treatment and care of children (see Guidance on practice). It is not a standard for paediatric care.
- 2 For the purposes of this document, the term 'family' is used to refer to any living arrangement whereby children under 16 years of age are looked after by one or more responsible adults. It does not suggest any specific notion of the relationships or sexuality of the caring adults within the group. HIV presents particular complications for families, and services should aim to minimise the disruption to day-to-day family life which these complications can generate.
- 3 Among people with HIV in England, the proportion who are heterosexual is rising. Improvements in antenatal diagnosis have allowed increasing numbers of mothers with HIV to be identified, and partly as a result, an increasing proportion of children and heterosexual men with HIV are also being diagnosed. The number of families needing HIV services is therefore growing.
- 4 Families affected by HIV may have children who are, or are not, infected. The number of uninfected children with infected parents is increasing. However, despite a significant reduction in the rate of mother-to-child transmission due to interventions before, during and after birth (see Standard 8), new diagnoses of HIV in children continue to occur. Among African communities in the UK affected by HIV, there are a number of children who became infected through mother-to-child transmission abroad. The average age of children living with HIV is increasing, mainly because of better life expectancy with ART.
- 5 The still relatively small number of families affected by HIV favours a service model where expertise is focused in specialist units supporting shared care arrangements with other units where fewer families access services. In addition to multidisciplinary clinical expertise, family services need the cultural competency to deal with the complexity of HIV-related issues, such as disclosure, avoiding breastfeeding, children's rights, and bereavement, as they arise in families from different cultural backgrounds. Experience in dealing with these complex family

issues has led to the development, in areas with higher HIV prevalence, of a number of dedicated family services designed to meet the treatment and care needs of both adults and children.

- 6 However, wherever there are families with HIV, there is a need for local service provision to meet day-to-day requirements, such as primary healthcare, community nursing and support for schooling. This is important for all children in families affected by HIV, whether infected, uninfected or of indeterminate status. Access to HIV specialist paediatric care as part of a network can allow for the majority of service delivery to take place at a local level whilst, when necessary, drawing on the expertise of a specialist centre which may be at a distance. This expertise is multidisciplinary, and will include monitoring and support (including psychological support) for the uninfected children of adults with HIV.
- 7 A seamless model of care would consist of all or most of the following, in line with national guidelines, either within one clinical setting or coordinated across several services within the network.
  - Management of HIV in pregnancy for HIV-positive women and their partners (see also Standard 8).
  - Care and follow-up of infants born to HIV-positive mothers, including those who are uninfected or of indeterminate status.
  - Health, psychological and social care and support for HIV-positive children and their siblings (whether or not infected) within a specialist setting.
  - Fully comprehensive treatment and care for adults and children.
  - HIV testing and care of adults when children have been identified first, and vice versa.
  - Enabling children infected from around the time of birth to learn gradually about their diagnosis at a pace suited to their neuropsychological development.
  - Transitional care for adolescents from paediatric to adult services in a manner sensitive to their needs.
- 8 The effect of social factors on health can be profound. Housing, welfare and other needs may be considered more pressing than healthcare by many families affected by HIV. Integrating social care with healthcare may improve service uptake and wellbeing, and specialised social services provision within family services can facilitate this (see Standard 6). Important aspects of social care include support for new mothers and their babies, such as free formula feed and adequate housing (see also Standard 8).
- 9 Provision of a life span model of family care allows transitional care for children to adolescent and adult services. The multidisciplinary team can provide continuity of support through these stages including management of complex issues such as parents' disclosure of their own and their children's HIV diagnosis, and identifying the appropriate age for transition from children's to adolescent and adult services. This continuity can also facilitate the development over time of young people's understanding of issues such as sexual health and the management of their condition.

### Key interventions

- Provision of multidisciplinary, multi-agency family services can ensure high quality care to meet complex needs in settings which ensure confidentiality for individuals and their families.
- Development of local specialist provision can be the most appropriate model where the level of need suggests this to be appropriate. Where numbers are small, shared care arrangements through the network with existing specialist centres can provide the best service for families.
- Integrating the provision of social care with healthcare, including specialist social services provision within established family clinics, can help meet the multiple needs of families affected by HIV.
- A life span model of family care, provided by a multidisciplinary team, can respond to changing needs over time and allow transitional care as children move to adolescent and adult services.

### Implications for service planning

- 10 The NHS and partner agencies should develop network arrangements to provide services to families affected by HIV. They should do this by:
  - fostering collaboration between acute trusts, PCTs, local authorities and voluntary agencies, including generic children's services
  - agreeing on the coverage and model of care for the family service network, including provision of specialist services (paediatric and adult service networks may not necessarily be co-terminous)
  - including all services offering HIV treatment and care to children and families within the network
  - continuing support for established family clinics which can act as a resource in network development and, where the level of need is high enough, establish new ones
  - developing, implementing and auditing protocols for provision of specialist family services and shared care, in order to help services meet all relevant national standards and guidelines
  - facilitating the involvement, within family clinic multidisciplinary teams or within the network, of a range of specialties and disciplines, optimally including:
    - adult and paediatric HIV specialist doctors
    - specialist nurses
    - specialist paediatric pharmacist
    - physiotherapy
    - occupational therapy
    - paediatric and adult psychology
    - health advisors

- paediatric and adult dietician
  - specialist social worker
  - specialist midwife
  - designated obstetrician
  - health advocacy and interpretation services
  - play therapist, nursery nurse or trained volunteer (to care for children during their parents' consultation)
  - GP and practice team
  - dental practitioner
  - ophthalmologist
  - laboratory services which enable blood samples to be taken locally
- facilitating access to paediatric and adult clinical trials and early access to therapies for all families with HIV
  - establishing an interface between primary care, social care and HIV specialist family services, so that provision is as seamless as local arrangements allow
  - putting clear referral pathways in place between family services and:
    - services for pregnant women with HIV (see also Standard 8)
    - adult HIV treatment and care clinics, including joint planning for transition (see also Standard 4)
    - GUM services (see also Standard 7)
    - relevant community-based groups and services
  - putting in place policies and protocols for managing HIV-related issues as they affect families, such as statutory regulations to deal with children
  - facilitating the development within services of competence to deal with HIV-related issues as they affect those from different cultures, including the complex needs and possible trauma which can affect refugees
  - designing services in a way that is sensitive to the needs of individuals within families, such as giving parents and carers the option to be seen in an adult setting alone, enabling older children to be seen by themselves if they choose, and providing HIV testing for children and young people in a manner appropriate to their age
  - facilitating the availability of appropriately trained personnel and materials to help children learn the full details of their diagnosis over time
  - providing sufficient staffing and IT support to enable the collection of robust data on inpatient and outpatient activity and outcomes for infected family members.
- 11 The NHS and partner agencies should enable healthcare and other workers providing care for families affected by HIV to receive appropriate and ongoing training, in order that they remain skilled in HIV and are able to meet the particular needs of families. This should include awareness and ongoing skills training on assessment and monitoring of child development.

## Guidance on practice

- 12 See Standard 4 for guidance on treating adults with HIV and Standard 8 for guidance on managing HIV and pregnancy.
- 13 It is anticipated that the Children's HIV Association of the UK and Ireland (CHIVA) will create and maintain a portfolio of guidelines addressing relevant aspects of multidisciplinary care for children with HIV. These are available from autumn 2003 via the BHIVA website ([www.bhiva.org](http://www.bhiva.org)) and will be adaptable for local use in shared care networks.

### Suggested audit indicators

Where family services include aspects of care covered by other standards, in particular Standards 7 and 8, those standards and their Suggested audit indicators should apply. In addition, indicators relating to the organisation of family services are suggested here.

- Participation in service network of all listed specialties and disciplines. Suggested monitoring tool – documented attendance at regular internal multidisciplinary team meetings, and at shared care network meetings.
- Development and implementation of protocols for shared care between specialist centres and local services. Suggested monitoring tool – evidence of regularly updated management guidelines available at all shared care centres, adapted for local use from CHIVA guidelines.
- Referral pathways in place for access to family services from all points in the HIV network.
- Data on attendances and outcomes of children and families which should be coordinated across the network.
- Percentage of HIV-infected children who have been notified to the National Study of HIV in Pregnancy and Childhood, via the British Paediatric Surveillance Unit, RCPCH.
- Percentage of annual follow-up forms returned to the National Study of HIV in Pregnancy and Childhood for each child.
- When more than one family member is infected and in regular follow-up, percentage of outpatient appointments that are coordinated for adult and child, where the family wants this.

For further reading see page 105

## Emergency care of people with HIV

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### Aim

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To improve health outcomes for people with HIV who are acutely ill, by enabling them to access a high standard of care in diverse emergency settings, including the recognition and management of undiagnosed HIV.

### Standard 10

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All people with HIV should have prompt access to rapid and effective treatment of all emergencies (HIV and other) by appropriately trained clinical healthcare workers.

### Rationale

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- 1 While HIV-related emergencies may occur during inpatient care, this standard specifically addresses those emergency situations where people with HIV are acutely ill but not HIV inpatients.
- 2 Although morbidity and mortality from HIV and AIDS have decreased dramatically over the last six years there is still a group of people with HIV who may require emergency care, including those who:
  - present with AIDS at the same time their HIV is diagnosed
  - remain immunocompromised despite treatment
  - have chosen to stop, or not to start, treatment
  - develop HIV-related tumours or infections
  - develop problems of drug toxicity.
- 3 HIV emergencies may be life-threatening and require both expert knowledge of HIV and expertise in the management of acutely sick patients. Access to high level medical and surgical care (including high dependency, intensive care, renal dialysis and emergency surgery), diagnostic procedures (including urgent tissue and organ biopsy, bronchoscopy, and endoscopy), and laboratory and radiological investigations (including magnetic resonance imaging (MRI)) is essential for optimising health outcomes.
- 4 Rapid, safe transfer of ill people, whose condition is known or suspected to be due to underlying HIV infection, to an appropriate specialist HIV centre (Standard 11) is likely to improve patient outcome.
- 5 To assess the cause of HIV-related acute illness often requires input from an HIV specialist. To ensure this occurs, critical care units within the network (including the private sector) need to be informed of the specialist HIV clinical support that is available locally or elsewhere with clear pathways for referral and access points for 24-hour advice.
- 6 Access to information about individuals' current HIV treatment and state of health is important for ensuring they receive the optimum care in emergencies. Ways of facilitating



this could include a patient-held card giving clear instructions about who to contact for such information, or giving brief clinical information such as viral load and CD4 count, current drug regimen and other significant details.

- 7 People may access emergency services on a number of separate occasions before HIV is recognised and diagnosed. All emergency services should be familiar with both emergency and non-emergency complications of HIV, to enable earlier diagnosis, more appropriate emergency care and referral for ongoing monitoring and treatment (see also Standard 2).
- 8 Developing and promoting networks of care can support the effective working of emergency services, and strengthen links with primary healthcare and specialist services. This will facilitate the transfer of care both from emergency to specialist or primary care settings, and from primary care to the emergency service setting.
- 9 Multidisciplinary team involvement and collaboration between medical specialties are key factors in successful emergency and critical care, and in the successful transition to follow-up in the community setting.
- 10 It is important that all people with HIV who present with conditions unrelated to HIV receive optimum emergency care, irrespective of their HIV status. As in all other healthcare settings, adherence to guidance for protection of clinical healthcare workers against infection with blood-borne viruses is important.

### Key interventions

- Increasing the skills and knowledge of clinical healthcare workers in all emergency centres to identify the symptoms of HIV-related illness (both emergency and non-emergency) irrespective of the background of the patient, can result in earlier diagnosis of HIV, more appropriate management of emergency care, and access to ongoing disease monitoring and treatment.
- Access to HIV specialist advice, whenever needed, can improve the management of HIV-related emergencies.
- Defining clear referral pathways and ensuring rapid, safe transfer of ill people with known or suspected underlying HIV infection to an appropriate HIV specialist service (see Standard 11) is likely to improve patient outcome.
- The availability of critical care facilities within, or in close proximity to, the specialist HIV service will optimise patient management in those who are critically unwell.
- Facilitating rapid access for emergency services to patients' medical information can improve the management of emergency care.

## Implications for service planning

- 11 The NHS should:
- facilitate the inclusion within HIV service networks of all services which may be used as entry points to the healthcare service by people with HIV requiring urgent medical attention. These include:
    - services which may be accessed in the developing stage of an emergency illness, including:
      - NHS walk-in centres
      - NHS Direct
      - GPs and other primary healthcare workers
      - out of hours services
      - clinical healthcare workers in prisons and other institutions
      - hospital and community drug services
    - services through which people with an established emergency illness are likely be admitted, including:
      - A&E departments
      - ambulance service
      - general medical wards
    - services into which they are likely to be admitted, including:
      - medical high dependency units
      - intensive care units
  - enable all healthcare workers in these services to develop basic knowledge and skills in HIV diagnosis and management appropriate to their role in the team, maintained and updated through ongoing training
  - provide regularly updated information for all healthcare workers in these services on where to obtain HIV specialist advice at all times
  - inform relevant clinical healthcare workers in HIV specialist services when they are responsible for providing this advice.
- 12 The NHS, and partner agencies where appropriate, should develop, implement and audit protocols for:
- the availability of 24-hour HIV specialist advice for all services which may provide emergency care for people with HIV, with clear points of access
  - clear care pathways for referral of people ill with known or suspected HIV to HIV specialist services, including rapid transfer when appropriate and safe (see also Standard 11)
  - emergency care for people with HIV (including those undiagnosed or whose diagnosis is not known) that respects their confidentiality
  - adherence by emergency care services to good practice guidelines for HIV testing (see Standard 2)
  - access to existing medical records for people who present for emergency care (whether or not they are known to have HIV)
  - the same quality of emergency care in non-HIV-related emergencies for those who are known or suspected to have HIV as for those who are not
  - adherence to national guidance on protection against occupational transmission of HIV and other blood-borne viruses (see Guidance on practice).

## Guidance on practice

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- 13 The RCP identifies the following areas of knowledge or skills that may be needed by physicians on acute medical take:
- management of the HIV-positive patient with respiratory symptoms
  - management of the HIV-positive patient with neurological symptoms
  - management of the HIV-positive patient with pyrexia of unknown origin
  - management of the HIV-positive patient with diarrhoea
  - management of needlestick injury from HIV-positive or high risk source
  - the stigmata of HIV-related immunosuppression
  - discussion and consent prior to HIV testing
  - the role of STIs in precipitating medical emergencies
- (Royal College of Physicians (2000) *Governance in acute general medicine. Recommendations from the Committee on General (Internal) Medicine of the Royal College of Physicians*. London: Royal College of Physicians.)
- 14 DoH guidance for clinical healthcare workers on protection against infection with blood-borne viruses (see Appendix A) states how to minimise the risk of HIV and other blood-borne virus transmission from patient to healthcare worker. This includes details of universal precautions which should be taken with all patients, whether known to be infected or not, in all healthcare settings. It is highlighted in this standard, because of the potential risks of exposure in an emergency setting. (UK Health Departments (1998) *Guidance for clinical health care workers: protection against infection with blood-borne viruses. Recommendations of the Expert Advisory Group on AIDS and the Advisory Group on Hepatitis*. London: Department of Health. Available at [www.doh.gov.uk](http://www.doh.gov.uk)).

### Suggested audit indicators

- Audit of all HIV-related deaths in the HIV network, including CD4, viral load and treatment history. Suggested monitoring tool – review of each death in a multidisciplinary meeting, leading to structured recommendations for improving practice, themselves to be the subject of future audit.
- Number of times people with HIV have presented to acute medical and emergency care departments prior to HIV diagnosis with conditions that may have been attributable to HIV disease. Suggested monitoring tool – multi-agency network audit.
- Number of AIDS-defining diagnoses reported from hospitals within the network, and level of involvement of specialist HIV centre with each.
- Percentage of cases where there was a delay of over 24 hours in obtaining an individual's medical records.
- Protocols in place in all A&E departments for the rapid transfer of care of HIV-positive patients to a designated HIV-experienced medical team and for access to specialist HIV advice. Percentage of staff aware of these protocols.
- Percentage of doctors and nurses in A&E and acute medical departments receiving induction training in recognition and immediate management of HIV-related conditions.
- Frequency of subsequent training (as above) and percentage of doctors and nurses attending.

For further reading see page 105

## Care of people with HIV during admission to hospital

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### Aim

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To reduce disease-related mortality and morbidity in people with HIV who require inpatient treatment as a result of their HIV infection, by enabling them to be cared for in hospital inpatient facilities for people with HIV within, or with close support from, a specialist HIV centre.

### Standard 11

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All people with HIV should have access to comprehensive specialist HIV inpatient treatment and care services and to a full range of supporting services and medical specialties.

### Rationale

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- 1 Although mortality and morbidity from HIV and AIDS have decreased dramatically since the introduction of HAART, there is still a group of people with HIV who require inpatient care. The presentation of the disease may be diverse and indicate complications associated with HIV or the individual's response to therapy.
- 2 The HIV epidemic in England is not evenly distributed, with two thirds of people with HIV living in big cities and a significant minority in rural areas. The use of managed networks to provide specialist inpatient care can help to ensure the consistency and quality of care for every person with HIV in diverse locations.
- 3 Care in a specialist HIV centre is likely to result in optimum outcomes for people needing inpatient treatment. If this is not possible or available, then the unit should be one with continuous support from a specialist HIV centre.
- 4 Clinical links need to be established between HIV specialists and a full range of medical, surgical, obstetric, critical care, cancer, paediatric and mental health specialties experienced in HIV. A full range of support services, including specialist pharmacy advice and all laboratory services, is essential in the management of HIV-related disease and needs to be readily accessible to HIV specialist services. Such support is essential to an integrated care package.
- 5 Service planning and networks should recognise that specialisation will differ between HIV treatment and care clinics. Occasionally, people with HIV who are critically unwell will need to be appropriately referred to other specialist medical or surgical centres within the network or outside it. Pathways for professional advice and referral back need to be in place for this to run effectively.
- 6 Critical care facilities within or in close proximity to the specialist HIV centre will optimise patient management in those who are critically unwell.

- 7 Negative-pressure isolation facilities for managing those with TB, where appropriate, and in line with British Thoracic Society recommendations, can reduce the risk of cross-infection to other patients with HIV (see Guidance on practice).
- 8 The rapid but appropriate transfer of ill people with known or suspected underlying HIV infection from emergency services or other hospital departments to an HIV specialist centre with critical care facilities, or to one supported by an HIV specialist centre, can improve patient outcome. Developing and promoting networks of care can underpin this process.
- 9 Multidisciplinary team involvement in hospital discharge planning, addressing psychological and social as well as medical care needs, will consolidate inpatient management and provide a smooth transfer of care to the outpatient environment (see Standard 6).

### Key interventions

- Timely access for people with HIV (who require inpatient care) to a specialist HIV centre, or to care with the support of such a centre, can improve outcomes. Also, referral back for more local care, when appropriate, can help provide continuity of care.
- Established links from specialist HIV centres to a full range of medical and surgical specialties experienced in HIV can improve the quality of care for people with HIV.
- Developing and supporting specialist HIV centres within managed HIV service networks can improve access to specialist inpatient treatment and care services for people with HIV.
- Multidisciplinary coordination of inpatient care and hospital discharge planning, with integrated assessment of social, psychological and healthcare needs, can facilitate the transfer to outpatient care and improve subsequent service uptake.

### Implications for service planning

- 10 The NHS, and partner agencies where appropriate, should develop, implement and audit protocols for:
  - the referral of people with HIV needing inpatient care to a specialist HIV centre
  - in situations where access to a specialist HIV centre is not available, referral to an inpatient environment with continuous input from a specialist HIV centre and with staff specifically trained in the treatment and care of HIV
  - provision of a full range of support services, such as pharmacy and diagnostics, for specialist HIV centres
  - involvement in HIV inpatient care of a full range of clinical specialties with experience of HIV, with clear referral pathways
  - referral of inpatients with HIV who have become critically ill to a more specialist centre, within the HIV network or outside it, with clear pathways for professional advice and two-way referral
  - access to, and use of, facilities necessary for HIV specialist inpatient care including:

- critical care
  - negative pressure isolation
  - multidisciplinary and multi-agency service provision for people in hospital with HIV
  - hospital discharge, including arrangements for social care, psychological support and primary healthcare, as well as HIV specialist outpatient care
  - referral to respite and palliative care, and to assessment for rehabilitation, with ongoing involvement of HIV treatment specialists in this care (see Standard 12).
- 11 The NHS and partner agencies should enable all healthcare workers involved in providing inpatient care for people with HIV to undertake ongoing professional education and training, so that they have the up-to-date knowledge and skills necessary to provide specialist management of HIV and related complications.
- 12 It is recommended that the NHS benchmark and audit outcomes of HIV inpatient care.

### Guidance on practice

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- 13 Treatment for people with HIV receiving inpatient care should be in line with current BHIVA guidelines. (BHIVA Writing Committee on behalf of the BHIVA Executive Committee (2003) British HIV Association (BHIVA) guidelines for the treatment of HIV-infected adults with antiretroviral therapy. *HIV Medicine* 4 (suppl 1): 1-41. Available at [www.bhiva.org](http://www.bhiva.org) – replaces guidelines issued in 2001).
- 14 The care of people with TB and HIV should adhere to the British Thoracic Society's recommendations on control and prevention of TB. (Joint Tuberculosis Committee of the British Thoracic Society (2000) Control and prevention of tuberculosis in the United Kingdom: Code of Practice 2000. *Thorax* 55: 887-901. Available at [www.brit-thoracic.org.uk](http://www.brit-thoracic.org.uk)).

### Suggested audit indicators

- Audit of admissions, referrals and outcomes (eg delays in admission, discharge or referral to other specialist services).
- Audit of all HIV-related deaths in the HIV network, including CD4, viral load and treatment history. Suggested monitoring tool – review of each death in a multidisciplinary meeting, leading to structured recommendations for improving practice, themselves to be the subject of future audit.
- Percentage of inpatients in the HIV network cared for in a specialist HIV centre or for whom advice was sought from a specialist HIV centre.
- Percentage of patients with presumed TB who were isolated appropriately.
- Evidence of multidisciplinary involvement in arrangements for discharge to the community.
- Availability of range of support services, eg pharmacy, psychology.
- Frequency of educational meetings and participation of multidisciplinary team.
- Percentage of specialist HIV centre clinical staff who undertake the minimum continuing professional development required by their specialist body.

For further reading see page 106



## Respite, rehabilitation and palliative care for people with HIV

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### Aim

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To maximise the quality of life, including end of life, for people with HIV through respite and palliative care appropriate to the stage of disease. To enable people with HIV-related cognitive impairment who would benefit from rehabilitation to receive it.

### Standard 12

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People with HIV should have access to palliative and respite care services that are sensitive to their specific needs at different stages of disease. Access to rehabilitation services for those with HIV-related cognitive impairment should be dependent on their current needs and their potential to improve.

### Rationale

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- 1 Advances in HIV care and therapy have resulted in significant improvements in survival for people with AIDS. The past decade has seen its conversion from a rapidly fatal to a manageable chronic disease. However, even in the era of HAART, AIDS remains an important cause of morbidity and mortality in many young adult populations, and attention to palliative and end-of-life issues remains an essential aspect of clinical care.
- 2 For some, HAART allows a full return to function and health, but others enter a chronic disease phase characterised by exacerbations and remissions related to HIV infection, concomitant diseases and the therapies themselves. Many of these problems require periods of respite and rehabilitation care.
- 3 Mortality among people with HIV has been steadily increasing from common co-morbidities such as hepatitis B and C, co-occurring malignancies (both AIDS-defining and non-AIDS-defining cancers), and substance misuse-related deaths. In addition, for some, the benefits of HAART are not always attainable.
- 4 The provision of specialist palliative care for people terminally ill with HIV can improve symptom control and their experience of the end of life.
- 5 As therapies for AIDS have become more specialised and potentially effective, palliative care has in many ways become more challenging. Many people with late stage HIV infection who, before the advent of new treatments, would have been considered to have terminal disease, now respond extremely well to HAART, but this is not always the case. With this uncertainty about outcome, the need to integrate palliative and curative approaches to care is evident and goals of HIV palliative care need to be redefined.
- 6 The psychosocial aspects of HIV (such as stigma, secrecy and discrimination) present particular complexities for the role of palliative care in HIV treatment. Palliative care (defined by the World Health Organisation (WHO) as 'total active care') considers the needs

of the whole person and therefore requires a multidisciplinary approach. It is particularly important to make sure the needs specific to HIV are met, but also the diversity of individuals' needs, given the varying and often marginalised nature of the populations affected by HIV, including young people, families, African communities, gay men, and injecting drug users. Many live in deprived conditions with a range of social and economic problems. Expectations of death and dying will be influenced by culture and lifestyle, while attitudes of the dying person, those close to them and their carers may be affected by the stigma associated with HIV, and resulting anxieties about confidentiality.

- 7 Much HIV palliative care can be delivered within generic palliative care settings. This means that a broad range of palliative care practitioners who are not HIV specialists require some skills and knowledge specific to HIV.
- 8 For some people with HIV-related cognitive impairment (sometimes known as HIV-related dementia), there is evidence that specialist rehabilitation can result in improvements in cognitive function.
- 9 Rehabilitation for people with HIV-related cognitive impairment requires specialist assessment and care, sensitive to the social and psychological issues associated with the disease. It should provide the opportunity to meet and gain encouragement from others in similar circumstances.
- 10 People who access services at a late stage of HIV disease (often from African communities) and with cognitive impairment require specialist multidisciplinary and culturally appropriate rehabilitation services.

### Key interventions

- Specialist rehabilitation for people with HIV-related cognitive impairment, following assessment of suitability for this intervention, can result in improvements in cognitive function.
- Provision of terminal care for people with HIV by specialists in palliative care can improve symptom control and end-of-life experience.
- HIV palliative care provided in generic palliative care settings can benefit from the support of specialist HIV services, to ensure HIV-specific expectations can be met, including addressing HIV-related stigma and respecting confidentiality.
- Close collaboration between all HIV care providers within a managed service network of care can ensure that palliative, rehabilitation and respite care is used effectively and appropriately.

## Implications for service planning

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- 11 The NHS and partner agencies should:
- undertake an assessment of the HIV respite, rehabilitation and palliative care needs of the local population
  - determine whether there is a sufficient 'critical mass' of care needed to allow the establishment or maintenance of HIV specialist palliative and/or respite care and, if not, whether such care should be commissioned from local generic or more distant specialist providers
  - establish the level of funding required to commission respite, rehabilitation and palliative care for all people with HIV who need them
  - use the flexibilities of *The NHS Plan* and the Health Act 1999, as well as the AIDS Support Grant, to commission these services (see also Standard 6)
  - involve both voluntary and NHS providers of respite, rehabilitation and palliative care, as well as service users in planning.
- 12 The NHS and partner agencies should develop, implement and review local arrangements and protocols so that:
- people with HIV have access to respite and palliative care, with clear referral pathways in place
  - all people with HIV and neurological or cognitive impairment have access to assessment to determine the suitability of rehabilitation care in their case, with clear referral pathways for those who will benefit from it
  - respite, rehabilitation and palliative care services work as part of a network in close collaboration with HIV treatment, social care, primary care and mental health services
  - respite, rehabilitation and palliative care services meet generic national standards of care (see Guidance on practice)
  - collaboration takes place between service networks across a wider geographical area where this is needed to ensure comprehensive services
  - all healthcare and other workers who may provide respite, rehabilitation or palliative care services for people with HIV receive training in basic skills and knowledge related to HIV
  - services providing respite, rehabilitation and palliative care for people with HIV are able to do so in a way which is culturally appropriate for the population groups most affected by HIV.

## Guidance on practice

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- 13 All palliative care services for people with HIV should adhere to current nationally agreed standards for palliative care.
- Chapter 11 of the Department of Health's national minimum standards for independent healthcare gives standards for hospices. (Department of Health (2002) *Independent healthcare national minimum standards regulations*. London: Department of Health. Available at [www.doh.gov.uk](http://www.doh.gov.uk)).
  - Topic 7 in the Department of Health's *Manual of cancer services standards* applies to palliative care in the secondary and tertiary care sectors for people with cancer. (Department of Health (2000) *Manual of cancer services standards*. London: Department of Health. Available at [www.doh.gov.uk](http://www.doh.gov.uk)).

- 14 Care homes, including those providing respite care for people with HIV, must adhere to the Department of Health's national minimum standards for care homes for younger adults and adult placements (for those aged 18 to 65). These standards are used by the National Care Standards Commission (NCSC). (Department of Health (2002) *Care homes for younger adults and adult placements. Care home regulations national minimum standards*. London: Department of Health. Available at [www.doh.gov.uk](http://www.doh.gov.uk))

### Suggested audit indicators

- Percentage of staff in palliative care services that care for people with HIV who have undertaken initial HIV-related training, and percentage undertaking ongoing training where appropriate.
- Development and implementation by a specified date of clear referral pathways from all HIV care providers to palliative care.
- Percentage of patients with cognitive or neurological impairment to receive assessment to determine suitability for rehabilitation.
- Percentage of those assessed as able to benefit from rehabilitation who are referred to specialist rehabilitation services.
- Development and implementation of clear referral pathways from all HIV care providers for people with HIV who require rehabilitative care.
- Implementation of care home regulations' national minimum standards by homes providing respite care for people with HIV.

For further reading see page 106

## Appendix A: Further reading

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## Appendix B

### Glossary of abbreviations

A&E	Accident and emergency
ABI	Association of British Insurers
AGUM	Association for Genito Urinary Medicine
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
BHIVA	British HIV Association
BMA	British Medical Association
CD4 cells	White blood cells or lymphocytes
CHAPS	Community HIV and AIDS Prevention Strategy
CHIVA	Children's HIV Association of the UK and Ireland
CMV	Cytomegalovirus
DoH	Department of Health
ECS	Elective caesarean section
ENB	English National Board for Nursing, Midwifery and Health Visiting
GMC	General Medical Council
GP	General practitioner
GUM	Genitourinary medicine
HAART	Highly active antiretroviral therapy
HFEA	Human Fertilisation and Embryology Authority
HIV	Human Immunodeficiency Virus
HPA	Health Protection Agency
ICH	Institute of Child Health
MedFASH	Medical Foundation for AIDS and Sexual Health
MRI	Magnetic resonance imaging
MSSVD	Medical Society for the Study of Venereal Diseases
NASS	National Asylum Support Service
NCSC	National Care Standards Commission

NHS	National Health Service
NONOPEP	Post-exposure prophylaxis after non-occupational exposure
NSF	National service framework
PACT	National Association of NHS Providers of AIDS Care and Treatment
PCT	Primary care trust
PENTA	Paediatric European Network for Treatment of AIDS
PEP	Post-exposure prophylaxis
PHLS	Public Health Laboratory Service
RCGP	Royal College of General Practitioners
RCOG	Royal College of Obstetricians and Gynaecologists
RCP	Royal College of Physicians
RCPCH	Royal College of Paediatrics and Child Health
SCIEH	Scottish Centre for Infection and Environmental Health
SSHA	Society of Sexual Health Advisers
SHIVAG	Scottish HIV and AIDS Group
SHA	Strategic health authority
STI	Sexually Transmitted Infection
TB	Tuberculosis
THT	Terrence Higgins Trust
WHO	World Health Organisation
YOI	Young offender institution

## Appendix C

### Membership of the advisory group and project team

#### *Advisory group*

##### *Chair*

##### **Patrick French**

Consultant in GU/HIV medicine, and Head of Medical Services, Mortimer Market Centre, Camden Primary Care Trust, London. Honorary Senior Lecturer, Royal Free and University College Medical School. Member of core group and steering group for development of the national strategy for sexual health and HIV.

##### *Members*

##### **Gary Brook**

Clinical Director of GUM, Central Middlesex Hospital, London. Deputy-Chair of BHIVA Audit Committee, Co-Chair of OLHIVE, Chair of North Thames HIV & GUM Audit/Education Committee.

##### **Sue Capstick**

Advanced nurse practitioner, sexual health, Morecambe Bay Primary Care NHS Trust, Lancaster. Member of the RCN sexual health forum.

##### **P Ariyaratne De Silva**

Consultant in Genito Urinary Medicine and HIV, Mid Yorkshire NHS Trust. Lead clinician with special interest in patient public partnership, and currently involved in the development and improvement of care pathways and integrated care for patients with HIV via patient journey mapping.

##### **Annemiek DeRuiter**

Consultant in GUM/HIV Guy's & St Thomas' Trust, London. Lead clinician for the Harrison wing (HIV outpatients); responsible for pregnant women with HIV. Co-author of 2001 BHIVA guidelines for the management of HIV in pregnancy.

##### **Ade Fakoya**

Consultant HIV/GU physician, Lead for HIV, Greenway Centre, Newham General Hospital, London. Co-Chair African HIV Research Forum.

##### **Mark Gompels**

Consultant in Clinical Immunology and HIV at North Bristol NHS Trust, United Bristol Healthcare Trust. Member of HIV Specialist Commissioning Committee for South-West England and National prospective monitoring group.

##### **George Kinghorn**

Consultant Physician in GU Medicine and Clinical Director for Communicable Diseases (incorporating Infectious Diseases & Tropical Medicine and Genitourinary Medicine), Royal Hallamshire Hospital, Sheffield. Immediate past-President of MSSVD; executive committee member of PACT, former executive committee member of BHIVA.

**Andrew Little**

Director of Positive Futures. User of HIV services. Chair of GRIPP (Greater Involvement of Positive People) a pan London working group, and member of London HIV Strategy Development Group.

**Jane Mezzone**

Sexual Health and Strategy Programme Manager, Department of Health.

**Anton Pozniak**

Consultant Physician and Hon Senior Lecturer, Kobler Clinic, St Stephens Centre, Chelsea & Westminster Hospital, London. Chair of PACT.

**Surinder Singh**

Half-time lead principal in general practice, SE London, and clinical lecturer in general practice at University College London. Co-author of two books on the community aspects of HIV/AIDS, longstanding member of the RCGP Sex, Drugs and HIV Task Group, recently completed two years as Lewisham PCT lead for Sexual Health.

**Dorinda Thirlby**

Clinic Manager/ Senior Health Adviser at Roehampton Clinic, Queen Mary's Hospital, London. Member of SSHA steering group for the Department of Health-funded Manual for Health Advising Practice.

**Paul Ward**

Deputy Chief Executive of Terrence Higgins Trust. Non executive Board member of South East London Strategic Health Authority. User of HIV services.

**Edmund G L Wilkins**

Consultant and Clinical Director in Infectious Diseases, Monsall Unit, North Manchester General Hospital. Member of BHIVA Executive Committee.

***MedFASH project team*****Kate French**

Organisation development consultant

**Breda Flaherty**

Organisation development consultant

**Ruth Lowbury**

Executive Director, MedFASH

**Iain Webster**

Administrator, MedFASH



### Membership of the advisory group and project team

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Members of the advisory group were selected to provide a range of experience and expertise in HIV service provision. The group as a whole advised on the project and the standards in general. In addition, each group member co-drafted one or more of the standards.

Kate French and Breda Flaherty supported and facilitated the group, Ruth Lowbury edited the standards, and Iain Webster provided administrative support.

**Literature** searching was undertaken by Freddy Abnoui and Celina Yong, and by the Health and Social Care Quality Centre, London.

## Appendix D

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### Consultation on development of the standards

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#### Consultation process

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The draft standards were developed by the project Advisory Group (see Appendix C for membership) with the project consultants and MedFASH staff.

Consultation on the first draft took place in June/July 2002 through:

- a one-day facilitated workshop with representatives of national stakeholder organisations (see below)
- three half-day facilitated workshops convened from a wide invitation list including local HIV health and social care service providers, service users and commissioners in North East London, North West England and South West England
- individual meetings with professional groups, voluntary sector organisations, and regional groups of providers
- request for written comments from all individuals and organisations invited to the above events
- availability of draft standards on MedFASH website with request for comment.

Following consultation on the first draft, comments were considered in detail by the Advisory Group and the standards were redrafted by MedFASH.

A number of expert readers (see below) were asked in October/November 2002 to comment on the revised draft and respond to outstanding queries.

Following further amendments, a penultimate draft was sent again to national stakeholder organisations in November 2002 and made available on the MedFASH website.

Final amendments were made in 2003.

#### Stakeholder consultation

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The following mostly national groups and organisations were invited to participate in the consultation process.

African HIV Policy Network (AHPN)  
Association of Genito Urinary Medicine (AGUM)  
Association of Directors of Social Services (ADSS)  
British HIV Association (BHIVA)  
British Infection Society (BIS)  
British Medical Association (BMA)  
British Psychological Society Faculty of HIV and Sexual Health  
Childrens HIV Association (CHIVA)  
Department of Health (DoH)

Dieticians HIV Association (DHIVA)  
English HIV Commissioners Group  
English HIV Policy Forum  
Faculty of Public Health Medicine  
Genito Urinary Nurses Association (GUNA)  
Haemophilia Society  
Health Development Agency  
HIV Mental Health team, Maudsley Hospital  
London HIV Commissioning Consortium  
Mainliners  
Mildmay Hospital UK  
Medical Society for the Study of Venereal Diseases (MSSVD)  
National Association of Nurses in Contraception and Sexual Health (NANCSH)  
National AIDS Manual (NAM)  
National AIDS Trust (NAT)  
National Association of NHS Providers of AIDS Care and Treatment (PACT)  
National HIV Nurses Association (NHIVNA)  
NAZ Project London  
NHS Regional Directors of Health & Social Care  
North Thames HIV & GUM Audit/Education Committee  
Outer London HIV Expediency (OLHIVE)  
Pan London HIV/AIDS Providers Consortium  
Public Health Laboratory Service (PHLS)  
Positively Women  
Royal College of General Practitioners (RCGP) Sex Drugs and HIV Task Group  
Royal College of Midwives (RCM)  
Royal College of Nursing Sexual Health Forum (RCN)  
Royal College of Obstetrics and Gynaecology (RCOG)  
Royal College of Paediatrics & Child Health (RCPCH)  
Royal College of Physicians  
Society of Sexual Health Advisers (SSHA)  
Terrence Higgins Trust (THT)  
The Network of Self Help HIV & AIDS Groups  
UK Coalition of People Living with HIV and AIDS (UKC)  
UK HIV Pharmacy Association

A range of individuals and other organisations gave written or verbal comments on the draft standards.

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## Expert advice and information

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The following provided expert advice and comment on the revised draft.

Dr Stewart Drage, Simon Ellis and Elaine Barnett-Page, Dr Barry Evans and Dr Kevin Fenton, Prof Ian Everall, Linda Johnson-Laird, Dr Margaret Johnson, Mick Matthews, Jonathan O'Sullivan, Andrew Pearmain, Prof Peter Robinson, Stephanie Sexton, Dr Gareth Tudor-Williams, Dr Mike Youle.

Many other individuals and organisations responded to queries and requests for advice during the development of the standards.



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### Recommended standards for NHS HIV services

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