

Service specification for HIV: British HIV Association response

Version 3 25012013

Do you find this clinical policy or service specification clear and comprehensive?

No. There are a number of areas that require clarification and/ or additional input.

1.1: Definition:

We recommend that this section include a clear acknowledgement that HIV infection can involve multiple organ systems and disease can be the result of severe immunodeficiency, the direct effects of HIV and potentially chronic immune activation. The issue is not just OIs and cancers but also non AIDS co-morbidities including direct effects of HIV and consequent end organ damage.

1.1: National policies:

Key standards should be updated to include BHIVA Standards of Care for people living with HIV 2013 (see evidence base section)

2.2: Service elements- overview:

- a) Further thought needs to be given to the terminology re 'provision of', 'access to' or 'referral to'. 'Provision of' implies that that this service element needs to be provided by the contracted service provider. 'Referral to' suggest a separate contract provider or service. A more appropriate term for some HIV service elements is 'access to' as this does not dictate the model of service provision which should be determined locally and in agreement with local commissioners. 'Access to' could mean either referral to a separate service or access via locally agreed joint specialist clinics or provision on site by dually trained staff (eg STI services). In general the term 'access to' is preferable to 'referral to' as this implies gives much greater flexibility in models of service delivery and commissioning arrangements that should be agreed locally.
- b) *'Referral to sexual and reproductive health service for annual STI screening'* is an inadequate statement to cover the need for and provision of or access to sexual health services for HIV positive people. HIV services should be both pro-active in screening and reactive to diagnosis and management of STIs in the interest of both patient care and the public health. Frequency of screening of STIs should be determined by clinical guidelines rather than stated in a service specification. Suggest this statement is amended to *'Access to screening diagnosis and treatment of sexually transmitted infections and the promotion of good sexual health'*.
- c) *'Referral to and liaison with primary care for management of non HIV care needs and for onward access to other specialities'*: This requires clarification; suggest add *'for non HIV care'* after *'other specialities'*. Direct referral to/liason with other medical specialities for management of HIV associated co-morbidities should continue to be possible where this is in the interest of patient care (see 'd' below) .
- d) *'Liaison with other specialities for appropriate management of HIV in the context of other co-morbidities, co-infections and for pregnancy'*: For reasons outlined in 'a' above suggest amend statement to *'Access to and or liaison with other specialities etc'*. The issue of direct

referral to other specialties is discussed in section 2.4 exclusion criteria and is subject to continuing discussions with named stakeholders.

- e) *'Promotion of HIV prevention including partner notification, sexual health risk behavioural support, peer and self-management and information'*. Not sure what HIV prevention means in this context, is this prevention of HIV transmission or prevention of disease progression. Suggest there is a separate statement on prevention of HIV transmission and a separate statement on promotion of self-management. Suggest amend to *'Assessment and promotion of reduction in HIV transmission risk including partner notification, HIV disclosure, testing of children of risk, promotion of safe sex practices, condom provision and behavioural interventions'*. Issues around use of ART as prevention including PREP are discussed separately. An additional statement on promotion of self-management should be added, see 'f' below
- f) The service element- overview should include a separate statement on the promotion of self-management. This is a key aspect for the long term management of a chronic medical condition. Suggest include the following statement: *'To inform, educate and provide appropriate information and support to patients about their HIV infection, psychological well-being, sexual health, HIV care and treatment with the aim to promote and enhance self-management'*.
- g) The service element overview should also include a statement on promotion of mental health and psychological well-being and management of HIV associated psychological difficulties as these are key to both ART treatment success, promotion of self-management and prevention of HIV transmission. Suggest add the following statements: *'Promotion of mental health, psychological and social well-being and welfare'* and *'Management and treatment of psychological and emotional difficulties associated HIV diagnosis, disease, treatment and prevention of HIV prevention'*.

2.2: Service elements- Inpatient services:

- a) *'Assessment, diagnosis and management of complications of HIV therapy requiring inpatient care (immune reconstitution syndrome (IRS))'* should be amended to *'Assessment, diagnosis and management of complications of HIV therapy requiring inpatient care including immune reconstitution syndrome (IRS)*. Not all complications of ART are IRS.
- b) *'Initiation of treatment for patients presenting with AIDS requiring inpatient care'*. The assumption treatment in this context refers to antiretroviral therapy (ART) and starting ART in patients with severe immunodeficiency including AIDS (in line with current national guidelines) who have required admission to hospital. Suggest this is amended to *'Initiation of antiretroviral therapy (ART) in patients presenting with complications of advanced immunodeficiency requiring inpatient care'*.
- c) There should be an additional statement on the assessment, diagnosis and management (where appropriate) of severe complications of HIV disease other than OIs or HIV associated malignancies where inpatient admission is required. This includes HIV associated neurological, kidney and haematological disease. Assessment and diagnosis may frequently occur on a specialist HIV inpatient unit before on ward referral to appropriate specialist medical specialities. This is the similar to the situation for HIV related malignancies. Suggest add the following statement: *'Assessment, diagnosis and management (where appropriate)*

of severe complications of HIV disease (other than OIs and HIV related cancers) requiring inpatient admission’.

2.2: Service elements: networks of care.

The BHIVA standards of care 2013 set out the care that should be accessible to all those living with HIV in the UK. Many different specialities and services are required at different stages in the course of HIV infection and will differ from individual to individual making it very unlikely that a single HIV clinical service will be able to deliver on all these aspects of care. ‘HIV Centres’ and ‘HIV Units’ were defined in the 2007 standards but not included in the 2013 standards, The difference between HIV Centre and Units is arbitrary and now redundant. All HIV outpatient services should be able to provide defined routine services and have access to more complex care where required. . Complex care needs may be provided by some HIV outpatient services but for others, referral pathways need to be in place as part of network arrangements. All HIV outpatient services should be able to provide or have access to all aspects of service elements for both routine and complex care needs either through own provision or through network arrangements. However configured, HIV specialist advice must be available 24/7. Specialised HIV inpatient service should be considered separately

2.2 Service elements: detailed pathway inclusions:

As per above, suggest do not separate into ‘HIV Centres’ and ‘HIV outpatient service’ as this separation is somewhat arbitrary and defines a model of care which should be determined locally. These sections need to be combined to clearly state what pathways are required for all HIV outpatient services, which might either be as onsite provision or as network pathway. The pathways for HIV specialised inpatient care should be detailed separately. In most cases HIV inpatient services will be provided by units who have large outpatient services, but this does not necessarily need to be the case and should be determined locally through agreed network arrangements and models care. The national service specification should define pathways of care not the model of care.

2.2: Service elements – general requirements:

Screening for and the assessment and management of HIV related co-morbidities (for example high CVD risk and reduced bone density) should be a function carried out by the HIV service in collaboration with primary care and specialist services

12th bullet point: should state ‘HIV related cancers’ not just ‘lymphomas’. This should also include Access to high resolution anoscopy and colposcopy together with other specialised services for the management of cervical and anal dysplasia.

There is no mention of training within the service specification. BHIVA recommends that services commissioned to provide HIV specialist in-patient care should be required to provide supervision and training in-line with national curricula for specialist trainees in GU Medicine and ID Medicine.

2.4 Acceptance criteria:

'All eligible patients will have access to care and treatment services irrespective of their sexual orientation, gender, race, disability or geographical location' should also include *'resident status'*, as this is no longer a barrier to access HIV treatment and care.

2.4 Exclusion criteria ARV prescribing:

'Informed by guidelines' suggest amend to *'informed by BHIVA guidelines'*. These are the only ART clinical guidelines in the UK that have NHS evidence accreditation by NICE and comply with a rigour of development.

2.5 Co-located services for Complex HIV care:

BHIVA believes that in the post April 2013 environment, the provision of the services needed by people living with HIV and the relevant referral pathways will be determined locally. This means that the service specification should list interdependent services for all HIV outpatient services, and not separates them into routine or complex care. All HIV outpatient services will need access to these additional services, some of which may be provided on site or via network arrangements. Co-located and interdependent services for HIV inpatients should be listed separately as part of the service arrangements for these services and may be dependent on the configuration of other specialist services locally/regionally. The only co-located services that are definitely required for inpatient services are HDU/ITU services and full range of imaging services. Acute medical and surgical services are required but co-location or onsite access may depend on configuration of specialist medical services locally or regionally. We refer the reader to standard 5 of the BHIVA 2013 standards

To ensure equity of quality and access to appropriate care BHIVA recommends (BHIVA Standards 2013) that no HIV service provider (large or small) should deliver services in isolation. HIV care for populations should be planned and delivered through networks. There is no single model for network design and commissioners will need to work with HIV and other health and social care providers, as well as service users, to identify how networks facilitate the delivery of effective and efficient care locally, regionally and nationally. Networks should facilitate integration of care between different providers and commissioners. The development of appropriate measures and tools to evaluate the patient experience across whole journeys of care and to respond accordingly will be vital to ensure success of networks. Once determined, networks of care should be formally defined, care pathways described and clearly communicated so that people with HIV, referrers and providers are all clear on the roles and responsibilities within networked arrangements.

In your opinion, does the clinical policy or service specification reflect the evidence base? Is there any additional information or evidence that you think should be taken into account?

No, several key publications are absent

The British HIV Association standards of care for people with HIV (2013) supersede the BHIVA 2007 standards that are cited throughout the service specification. BHIVA recommends that the 2013 standards should be endorsed by the NHS CB and used as the key reference throughout the service specification. The document required is available at available at

<http://www.bhiva.org/documents/Standards-of-care/BHIVASTandardsA4.pdf>

The use of antiretroviral therapy to reduce onward transmission of HIV is endorsed by The British HIV Association and the Expert Advisory Group on AIDS. BHIVA recommends that the NHS CB make it clear within the service specification that this is an integral aspect of the appropriate treatment and care for people with HIV. The position paper supporting this statement is available at

<http://www.bhiva.org/the-use-of-ART-to-reduce-HIV-transmission.aspx>

In your opinion, is this clinical policy or service specification inclusive of all people who may be affected by it including minority groups? Please provide examples with your response:

HIV particularly affects already marginalised populations, and further complicates already difficult lives. The service specification is not robust enough on ensuring that services are delivered in the context of the social and cultural issues faced by people with HIV. In the UK people with HIV face a greater number of barriers to service access than the HIV negative population. HIV-associated stigma has many negative effects on the lives of people with HIV, undermining confidence and acting as a barrier to service uptake and utilization. Fear of stigma discrimination and rejection means that people with HIV frequently do not disclose their medical condition outside their clinical teams and are fearful about engaging with services where their confidentiality may be compromised. People from minority ethnic backgrounds and communities are disproportionately affected by HIV and HIV associated stigma is frequently very high in many of these communities further exacerbating communication issues and access to care. The service specification should make explicit a requirement that HIV care is delivered in a culturally competent fashion and that appropriate access to language services is available. Informal translation and advocacy is not appropriate in the context of HIV service provision. Appropriate peer support enables people with HIV to develop confidence and gain information and skills from others in an easily identifiable and applicable way, which is critically important for all other aspects of self-management, yet it is far from clear how these essential services will be commissioned after April 2013.

Do you think that this service specification or clinical policy as described will enable all relevant sections of the population to access the service?

The service specification does not articulate adequately the importance of collaborative working between service providers to ensure equitable access to high quality care. This is an opportunity to ensure that the commissioning of HIV care is equitable and accessible for everyone with HIV in the UK. Although the prevalence of HIV varies considerably across the UK, everybody living with HIV must have equitable access to high quality treatment and care regardless of where they live or which providers they use. Clinical safety and service sustainability is dependent on a critical mass of staff, expertise and resources. Collaborative working arrangements within and between HIV service providers are essential for both equitable delivery of care and for maximising efficiency.

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

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

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

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

Can you envisage any barriers to putting this service specification or clinical policy into practice from April 2013?

People with HIV require integrated care, which is threatened from April 2013 by the new arrangements

Currently HIV services in England provide good care and have demonstrable excellent clinical outcomes, better or equal to those in other developed countries. With the change in commissioning arrangements, the challenge is to ensure the continued provision of best care and to continue to change and adapt service provision to reflect the requirement for chronic condition management. A key aspect of chronic condition management is integrated care between primary and secondary services and promotion of self-management. HIV disease is a long term chronic condition often requiring input from multiple specialities as well as HIV specialists and community and primary care services to enable best practice and outcome.

The change in commissioning arrangements poses a huge challenge to HIV services to maintain and enhance best practice and outcome through the development of an integrated care model for management of HIV as a long term chronic medical condition. The development of HIV service specifications is a huge opportunity to promote and deliver such a model. The draft HIV service specifications do describe the requirement for HIV specialist care and acknowledge the input required from other medical specialties and primary and community care. They also acknowledge the difficulty in achieving this because of the involvement of different commissioning arrangements for different aspects of care. The major threat to HIV services is the dis-integration of service provision because of the failure of commissioners (NCB, CCGs and local authorities) to collaborate and agree provision of integrated care. The HIV service specification is a potential powerful tool to ensure this occurs. It should not be just a description of what the NCB will commission but also a powerful lever to ensure provision and access to other services that are an essential requirement for best HIV care. Wording within the service specification should be strengthened to reflect and promote this need for close collaboration between different commissioners. An example of this is the potential dis-integration of HIV and sexual health services. Collaboration between designated area teams within the NCB responsible for

commissioning HIV services and local authorities responsible for sexual health services must be enabled and encouraged.