#### B06/S/a

# 2013/14 NHS STANDARD CONTRACT FOR SPECIALISED HUMAN IMMUNODEFICIENCY VIRUS SERVICES (ADULTS)

#### **SECTION B PART 1 - SERVICE SPECIFICATIONS**

Service Specification No.	B06/S/a
Service	Specialised Human Immunodeficiency Virus Services (Adults)
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

## 1. Population Needs

#### 1.1 National/local context and evidence base

#### Definition

Human Immunodeficiency Virus (HIV) is a virus that infects and destroys cells responsible for combating infections, leaving the body susceptible to diseases it would normally be able to fight.

Without treatment, the immune system can be compromised and rare infections or cancers develop. When these are particularly serious, the person is said to have AIDS (Acquired Immune Deficiency Syndrome).

Disease progression is monitored primarily through markers of immunity (CD4 count) and virus (viral load). Antiretroviral therapy (ARV) is used to reduce virus to protect immunity. ARVs require high levels of adherence to be effective and patients can become resistant to certain drugs, requiring switching. There are a number of drug-to-drug interactions with ARVs which need to be avoided or managed. In addition to specialised HIV services, meeting the needs of HIV infected individuals relies on access to other services including sexual health and reproductive health, mental health, antenatal and third sector support services.

HIV can only be passed on through infected blood, semen, vaginal fluids or breast

milk. HIV is mainly transmitted through vaginal or anal intercourse without a condom or by sharing a needle or syringe with someone who's living with HIV.

# **Testing**

HIV is diagnosed via a blood test. Individuals at risk of HIV can access through sexual health and reproductive health services, GP practices, antenatal clinics and also through local HIV voluntary organisations or substance misuse services. HIV testing may also be recommended by other clinicians where patients have symptoms of HIV. Testing guidelines for the UK were produced in 2008. http://www.bhiva.org/HIVTesting2008.aspx

## **Incidence and prevalence**

National HIV surveillance is undertaken in the UK by the Health Protection Agency (HPA) / Public Health England. The overall prevalence of HIV includes the number of undiagnosed as well as diagnosed people infected with HIV. In 'HIV in the United Kingdom: 2012 Report', the Health Protection Agency reported the following data for 2011

http://www.hpa.org.uk/Publications/InfectiousDiseases/HIVAndSTIs/1211HIVintheUK2012/

- The estimated number of people living with HIV in the UK was around 96,000, of whom 24% remained undiagnosed and therefore unaware of their infection.
- UK prevalence is estimated as 1.5 per 1000 for all ages. Prevalence in men who
  have sex with men is estimated as high as 47 per 1000 and 853 per 1000 in
  London. Prevalence in Africans is also high at 47 per 1000.
- A total of 6,280 people were newly diagnosed with HIV infection and almost half were diagnosed late (CD4 cell count <350 cells/mm3). People diagnosed late have a tenfold increased risk of dying within a year of diagnosis.
- New diagnoses of HIV among men who have sex with men (MSM) was the highest ever number reported in one year (3,010). Almost a quarter are thought to have acquired their infection in the previous 6 months.
- Of the 6,280 people newly diagnosed, an estimated 4,000 probably acquired their infection within the UK.
- 73,660 people accessed HIV care representing a 58% increase since 2002. The
  most deprived areas in the UK also have the highest HIV prevalence; this health
  inequality is particularly evident in London where diagnosed HIV prevalence is as
  high as 8 per 1,000 in the most deprived areas.
- 88% of people for whom treatment was indicated were receiving ARVs and 87% of people receiving treatment were virally suppressed.

Research published in 2011 indicated that life expectancy in people treated for HIV infection has increased by over 15 years during 1996-2008, but is still about 13 years less than that of the UK population. Earlier diagnosis and subsequent timely treatment with ARVs increases life expectancy. <a href="http://www.bmj.com/content/343/bmj.d6016">http://www.bmj.com/content/343/bmj.d6016</a>

Surveillance of HIV pregnancy is undertaken by the National Study of HIV in Pregnancy and Childhood (NSHPC). Over 1300 pregnancies were reported in women

living with HIV in 2010.

All patients with diagnosed HIV infection need to be in HIV care for monitoring of disease progression and treatment as required.

# **National Policy Initiatives**

Relevant national policy initiatives include:

2013/14 NHS Outcomes Framework

## **Health protection**

National surveillance of HIV through reporting to the Public Health England (formerly HPA) SOPHID / HIV & AIDS Reporting System (HARS), the Medical Research Council (MRC) and NSHPC. Some local surveillance schemes are in place.

NICE guidance to promote HIV prevention – 'Increasing the uptake of HIV testing among black African in England (PH33)' and 'Increasing the uptake of HIV testing among men who have sex with men (PH34)' -  $\frac{1}{2}$ 

http://www.nice.org.uk/guidance/phg/published/index.jsp?d-16544-p=2

Expansion of HIV testing beyond sexual health settings in order to reduce the 'undiagnosed fraction' of those infected with HIV but unaware of their status – http://www.bhiva.org/

Reduction in the late diagnosis of HIV (defined as a CD4 count of less than 350).

'Don't forget the children' report to promote testing of children of HIV positive adults <a href="http://www.bhiva.org/DontForgettheChildren.aspx">http://www.bhiva.org/DontForgettheChildren.aspx</a>

### **Health improvement**

- Antenatal HIV screening to prevent mother to child transmission of HIV and improve outcomes for women as per 2013/14 Public Health Outcomes Framework.
- Employment for those with a long-term condition.

Also relevant are international clinical initiatives currently under development or research. These include:

- Treatment as prevention' this is a term used to describe initiation of ARV treatment of HIV positive adults irrespective of CD4 count primarily for the purpose of prevention of onwards transmission of HIV.
- Pre-Exposure Prophylaxis involves use of ARVs in adults who are HIV negative but who are at high risk of HIV infection. Treatment is provided in <u>advance of</u> <u>sexual exposure unlike post exposure prophylaxis where treatment is provided</u> following risk assessment of sexual or other exposure.

These initiatives will require a process of evaluation and approval before being

commissioned either by HIV prevention commissioners or NHS England.

# Key documents / evidence base

Apart from NICE public health guidance on expansion of HIV testing, NICE guidance does not currently exist for HIV. In the absence of this, expert clinical opinion and surveillance and cohort studies provide evidence to support service delivery. Guidelines and standards are produced by the relevant professional bodies and these provide advice for developing and agreeing commissioning policies.

Key surveillance and cohort data can be found at

http://www.hpa.org.uk/HPA/Topics/InfectiousDiseases/InfectionsAZ/1200660065903/http://www.ukchic.org.uk/ (The UK Collaborative HIV Cohort Study)http://www.chipscohort.ac.uk/default.asp (Collaborative HIV Paediatric Study)http://www.nshpc.ucl.ac.uk/ (The National Study of HIV in Pregnancy and Childhood)

The British HIV Association (BHIVA) is the professional body for HIV. Following assessment of its process for consideration of clinical evidence, BHIVA has been accredited as a guideline writing organisation by NICE from 2012. Key guidelines relevant to this specification as at February 2013 can be found at <a href="http://www.bhiva.org/PublishedandApproved.aspx">http://www.bhiva.org/PublishedandApproved.aspx</a> and are

- British HIV Association: Treatment of HIV-1 infected adults with anti-retroviral therapy (2012).
- British HIV Association: Guidelines for the management of HIV infection in pregnant women (2012).
- British HIV Association/British Infection Association: Treatment of opportunistic infections in HIV positive individuals (2011).
- British HIV Association: Treatment guidelines for Tuberculosis in HIV positive individuals (2011).
- British HIV Association: HIV associated malignancies (2008).
- British HIV Association: Immunisation of HIV-infected adults (2008).
- British HIV Association: Management of coinfection with HIV-1 and hepatitis B or C virus (2010).
- British HIV Association: Routine investigation and monitoring of adult HIV-1infected individuals.
- Guidelines for Prevention and Treatment of Opportunistic Infections in HIV-Infected Adults and Adolescents (CDC, NIH: 2009).

Also relevant are guidelines promoting HIV testing

- UK National HIV guidelines for HIV testing (2008).
- UK National guideline on safer sex advice (2011).
- 'Don't forget the children' Guidance on the HIV testing of children of HIV positive parents (2009).
- UK Guideline for the use of post exposure prophylaxis for HIV following sexual exposure (2011).

The British Association for Sexual Health and HIV (BASHH) has also produced

relevant guidelines <a href="http://www.bashh.org/">http://www.bashh.org/</a>

Key standards relevant to this specification are

- Standards of Care for People Living with HIV in 2013 http://www.bhiva.org/standards-of-care-2013.aspx
- Work is underway regarding shared care with primary care
   <a href="http://www.bhiva.org/PrimaryCommunityCare.aspx">http://www.bhiva.org/PrimaryCommunityCare.aspx</a> Further guidelines for services in appropriate management of HIV patients can be accessed at <a href="http://www.bhiva.org/">http://www.bhiva.org/</a>
- Standards for psychological support for adults living with HIV, 2011 British Psychological Society in association with BHIVA and Medfash <a href="http://www.medfash.org.uk/uploads/files/p17abjilhe7as89k45i1icg1f121.pdf">http://www.medfash.org.uk/uploads/files/p17abjilhe7as89k45i1icg1f121.pdf</a>
- Standards of Care for Children with HIV are due for publication by CHIVA in 2013. Whilst these are relevant to Service Specification B6b, they relate to this specification in relation to collaborative management of HIV in pregnancy.

# 2. Scope

# 2.1 Aims and objectives of service

#### Aim

The aim of Specialised HIV Services for Adults (Outpatient and Inpatient Services) is to provide specialist assessment and ongoing management of HIV and associated conditions in order to support patients to stay well (reduced mortality and morbidity) and to reduce the risk of onward transmission of HIV. The service aims to ensure that the outcomes, wellbeing and quality of life of adults with HIV are maximised.

### **Objectives**

The service will deliver this aim by:

- Providing high quality treatment and care services to adults with HIV which are responsive to local prevalence and which facilitate and promote retention in care.
- Ensuring adults with HIV are central to decisions about the management of their condition, reflected in their care plan and including relevant support to promote self management.
- Providing prompt assessment and management of adults diagnosed with HIV through outpatient services and inpatient services.
- Delivering services by a Multidisciplinary Team (MDT) under the direction of a qualified consultant physician, including through formalised networked arrangements to balance quality of care, productivity and access. MDT arrangements also include working across specialities.
- Ensuring timely initiation and effective ongoing management of ARV treatment that enables patients to achieve and maintain undetectable levels of virus. This to be done through provision of treatment, adherence, including support and

support.

- Case management appropriate to the clinical and holistic needs of the patient.
- Providing onward referral (via GPs as appropriate) to meet the wider clinical and holistic care needs of adults with HIV.
- Agreeing pathways which define responsibility for meeting non HIV needs of
  patients and identify shared care. These will include but not be confined to:
  primary care, sexual health, social services, family services, psychological
  support, community and third sector services, drugs & alcohol services and
  maternity services. Particular attention needs to be paid to simplifying pathways
  for vulnerable groups such as prisoners, migrants and those with learning
  disabilities.
- Supporting adults with HIV to minimise risk of transmission of HIV to others. The service will provide (under a sexual health specification) or refer to services for partner notification and HIV testing of sexual partners and family members at risk of HIV infection.
- Supporting the appropriate management of pregnant women with HIV, including ARV initiation to prevent mother to child transmission (see Service Specification B6b).
- Contributing to national and local HIV surveillance schemes.
- With consent of patients, ensuring effective communication and shared care arrangements with other services for the benefit of patients.
- Participating in and implement the results of national and local audits, including Mortality and Morbidity Reviews and learning from very late diagnosis case review.

# 2.2 Service description/care pathway

This specification identifies the requirements of specialised HIV services for adults. Specialised HIV services are part of a care pathway that includes services beyond the scope of this specification which are commissioned at a local level. The effectiveness of specialised HIV services depends on other elements of the HIV care pathway being in place and effectively coordinated.

## **Service elements - General requirements**

The provider is responsible for collaborating with other health, social care and third sector organisations as appropriate to help ensure the holistic needs of patients are met. In particular this is likely to include:

- GPs and primary care and supporting patients to register / disclose to their GP.
  Regular communication with GPs where patients have disclosed their status will
  be implemented to avoid drug to drug interactions and to provide a point of
  contact in the event of primary care queries.
- Mental health services, substance misuse services, antenatal services and social services.
- Community services provided by third sector and other organisations. These services can provide important support on long-term condition management,

adherence, advocacy and counselling. All patients will be informed of these services and access facilitated, and providers will ensure regular communication and effective referral pathways to these services.

- Supporting the transition of young people with HIV from paediatric HIV to adult HIV services.
- Particular efforts to support care pathway simplification for vulnerable people with HIV e.g. prisoners, migrants, people with learning disabilities.

The provider is responsible ensuring clinically safe and appropriate facilities for service delivery, including designing services to promote confidentiality and improved patient experience.

The provider is responsible for ensuring transfer of patient notes within 2 weeks of receipt of request / referral for patients choosing to transfer their care or as part of shared care arrangements.

The provider is responsible for providing timely, accurate and complete surveillance and clinical data to Public Health England (formerly HPA), NSHPC and other relevant national and local surveillance schemes. This data reporting is mandatory for all providers seeking to be commissioned and funded for specialised HIV services. In the absence of patient identifiable data, commissioners depend on surveillance data for commissioning purposes. Other surveillance / cohort reporting is also expected to support ongoing development of HIV outcome measures and to monitor quality.

The provider is responsible for producing and publishing documentation which clearly defines arrangements for access to 24-hour on-call/referral advice. These must be publicised to acute medical and accident and emergency departments within the area. Whilst it is not commissioned in this specification, the provider is likely to be required to provide advice on Post Exposure Prophylaxis following Sexual Exposure or other exposure (PEPSE / PeP).

Appropriate laboratory services to support access to all relevant tests recommended in BHIVA guidelines for monitoring patients on and off ARVs.

All HIV outpatient providers will offer routine clinics and aim to design services around the convenience of patients, making use of technology and other resources to meet local need.

Where available, all outpatient providers will facilitate home delivery of ARVs using the suppliers included in local, regional or national procurement frameworks agreed with commissioners. Patients for consideration for home delivery will be those who are stable on treatment.

HIV outpatient services may take place in a range of settings as part of a delivery model to be agreed with the commissioner. As models of care develop, some patients may also access services virtually. In all cases, care management must be overseen by a consultant-led specialist HIV team. Less frequent / virtual monitoring will depend on agreement with the commissioner as to segmenting of the patient cohort and agreed definitions of stable / other patients. HIV inpatient care will take place in acute

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providers who are able to demonstrate that they meet the specified criteria.

All providers to deliver services in accordance with principles of clinical and cost effective prescribing; management of HIV as a long term condition supported by primary care and patients as self managers; normalising HIV to ensure effective care of patients with co morbidities and an ageing HIV population; and limited financial resources which must be deployed effectively to maximise treatment opportunities for all patients.

All providers to maintain complete and accurate electronic records for all patients to ensure effective clinical management of patients transferring from services and to enable service planning, commissioning, monitoring and payment. These to be kept in accordance with NHS standards of confidentiality and clinical safety, and record keeping guidance. Consent for sharing of information must be documented.

## Service elements – models of care requirements

In line with BHIVA Standards for HIV Care 2013, this specification does not define the exact model of care delivery. The demography of HIV within the UK makes it very unlikely that there will be a "one size fits all" model of service delivery. The standards make clear that whatever the size of the service, it shall not operate in isolation but as part of network arrangements. Local arrangements and networks will be necessary to ensure equity of access for local needs, to protect quality and to improve productivity.

The arrangements for care must be documented to make clear to patients and care providers how pathways operate. In some areas this may result in centralisation of services in one location. In others, a lead provider model of commissioning may be more appropriate. Greater use of technology may see more virtual management of stable patients and in some areas outreach services may provide greater engagement in care.

Service configuration will also recognise that some complexities of HIV disease are so rare, in order to maintain safe and sustainable services, it is best to centralise services.

Specific configurations are likely to be affected over the next 2 years as a result of

- Developing integrated sexual health and reproductive health services. Services
  are increasingly likely to move into community settings and be subject to
  procurement exercises. These changes will impact on HIV service provision
  where this has been integrated with sexual health.
- Changes to existing Sexual Health and HIV Managed Clinical Networks as a result of changing commissioning responsibilities.
- Responding to local needs assessments and availability of local expertise.
- Clinical agreement on the criteria for critical mass of staff and patients for HIV outpatient and inpatient services to better meet needs, protect quality, improve productivity and make best use of scarce clinical expertise.

Changes in the next 12 - 24 months are likely to require further updates to this specification.

# Service elements – patient involvement and self management requirements

# Requirements include:

- Service user involvement in decisions about their own care and in ways which gather feedback to influence design and improvements in service delivery.
- Case management approach with a focus on self-management and enabling adherence.
- Access to health advisor/counsellor and other forms of emotional and psychological support (e.g. peer support) as required to address psychological and emotional difficulties associated HIV diagnosis, disease, treatment and prevention of HIV prevention. These services are sometimes provided by community or third sector providers.
- Access to treatment support including patient education, delivered in partnership with community or voluntary providers.
- Personalised information and discussion to support and enable patients in sharing in decisions about their individual care. Patient consent to be sought and documented for sharing information which supports integrated care.
- Health promotion approach / pathways to ensure adults with HIV are supported to improve their health and wellbeing.

# Service elements – outpatient service requirements

As a minimum, HIV outpatient services will provide:

- Assessment of newly diagnosed HIV patients on the same day of referral for symptomatic patients and within 2 weeks of diagnosis for asymptomatic patients.
- Screening, diagnosis and management of complications of HIV and / or ARVs.
- Ongoing assessment, monitoring and management of patients starting, switching and who remain on ARVs. This to be undertaken by an appropriately qualified MDT under the direction of a qualified consultant physician, with access to specialist HIV pharmacy services. Treatment plans developed in line with BHIVA and other relevant guidelines, standards or policies. Provision of (or access to via documented and agreed network arrangements) specialist MDT review of patients with detectable virus and two-class or greater and/or HIV multi-drug resistance. The MDT to consist of at least one consultant virologist, two HIV consultants and a specialist HIV pharmacist.
- Provision of specialist pharmacy services and appropriate treatment adherence support for patients on ARVs.
- Referral to sexual health and reproductive health services for partner notification (PN), annual Sexually Transmitted Infections (STI) screening, contraception and pre-conception care.
- Referral to and liaison with primary care for management of the non-HIV care needs of patients and for onward access to other specialties.

- Liaison with other specialties for appropriate management of HIV in the context of other co morbidities and co infections. Provision of (or access to via documented and agreed network arrangements) joint HIV co-infection clinics (e.g..TB, Hepatitis, HIV associated neurocognitive impairment or other co-infections / other co-morbidities), or to respond to local needs such as family clinics, transition clinics etc.
- Provision of (or access to via documented and agreed network arrangements) specialist management of pregnant women with HIV, including prescribing to prevent mother to child transmission.
- Referral to and liaison with third sector, community and social care providers for non specialised HIV care and support needs and services.
- Assessment and promotion of reduction in HIV transmission risk including access to partner notification, testing and behavioural interventions.
- Assessment and promotion of reduction in HIV disease progression including access to behavioural interventions, peer support, support for self management and information.
- Assessment of HIV-associated lipodystrophy and referral for HIV-led non surgical management for moderate – severe facial symptoms and onward referral to plastic surgery as appropriate.
- Operation within agreed local documented pathways / networked arrangements including for referral for inpatient care and 24/7 access to emergency treatment and advice.

# Service elements – inpatient service requirements

As a minimum, HIV inpatient services will provide:

- Assessment, monitoring and management of patients by appropriately qualified HIV specialist MDT with 24/7 consultant cover or documented network arrangements to achieve 24-hour on-call/referral advice. These must be publicised to acute medical and accident and emergency departments within the area.
- Management of initial HIV diagnosis where this occurs during inpatient admission.
- Assessment, diagnosis and management of opportunistic infections related to HIV infection, including Initiation of ARVs in patients presenting with complications of advanced immunodeficiency requiring inpatient care.
- Assessment and diagnosis of HIV related malignancies and onward referral for specialist management.
- Assessment, diagnosis and management of complications of ARVs requiring inpatient care including immune reconstitution syndrome (IRS).
- Assessment, diagnosis and management (where appropriate) of severe complications of HIV disease (other than OIs and HIV related cancers) requiring inpatient admission.
- Network protocols/formalised pathways for integrated care for those conditions requiring specialist input, such as lymphoma, multi-centric Castleman's disease, end-organ liver and renal disease. Liaison with other specialties for appropriate management of HIV in the context of other co morbidities and co infections.

- Facilitation of linkage to specialised HIV outpatient care on discharge, ensuring patients are not lost to follow up.
- Provision of specialist advice relating to HIV for inpatients with non HIV related admissions to other specialities where appropriate.
- Effective discharge planning including the timely sharing of care plans.
- Referrals must be accepted in a timely manner. For example, inpatient referrals shall be accepted within 24 hours. Centres unable to accept a referral from must assist in identify an alternative referral pathway.

Adult HIV patients may require ITU care as part of their inpatient admission. This is an appropriate part of care for effective management of patients depending on need.

Providers of HIV inpatient care must provide the service in line with requirements set out in the BHIVA Standards 2013 and listed below. The requirements for co-location are restated in section 2.5.of this specification:

- Provision of 24-hour access for acute care.
- Co-location with HDU and ITU services with appropriate escalation of care to HDU and ITU when indicated.
- 24-hour availability of pharmacy services and access to specialist HIV pharmacist advice.
- An HIV specialist consultant physician-led multidisciplinary team (MDT).
- A nursing team with HIV specialist nursing skills and expertise.
- 24-hour availability of HIV specialist inpatient consultant advice and expertise (locally or via a network).
- Access to diagnostic laboratory services as required.
- Access to other medical and surgical specialty advice and services when required.
- Access to psychosocial and welfare advice and support.
- Access to peer support.
- Access to dietetic, physiotherapy, occupational therapy and speech and language services, including assessment and provision of inpatient rehabilitation.
- Provision of 24-hour access to and use of on-site negative pressure units.
- Access to a full range of on-site imaging services.

# Service elements – Staffing and critical mass

The Specialised HIV Service shall be provided (directly or via formalised network arrangements) by a HIV specialist consultant-led multidisciplinary team. The exact composition of the team will depend on the location of the service but is likely to include:

- A substantive body of consultant physician expertise covering a range of clinical aspects of HIV, able to provide care directly and to advise and support colleagues in other services.
- Where HIV consultant physician care is additional to general medical cover, this to be provided on 24/7 rota.
- One or more dedicated HIV specialist pharmacists.

- Senior specialist clinical nurses (including Community Nurse Specialists).
- Access to specialist virologist.
- Access to allied health professional input such as occupational therapy, physiotherapy, clinical psychology and dietetics.
- Access to health advice.

All staff to be able to work across organisational boundaries and support colleagues involved in delivering care as part of network arrangements.

Requirements for qualification, training, standards and CPD are set out by the professional bodies BHIVA, NHIVNA and HIV Pharmacists.

More detailed staffing profiles and critical mass of staff / patients to be subject to further work by the HIV CRG in 2013/14.

## 2.3 Population covered

# Patients covered by NHS England

The service outlined in this specification is for patients ordinarily resident in England\*; or otherwise the commissioning responsibility of the NHS in England (as defined in Who Pays?: Establishing the responsible commissioner and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges: <a href="http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH">http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH</a> 127393

• From October 2012, regulations changed to include HIV care and treatment as an exemption to the charging regulations.

(\*Note: for the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP Practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP Practice in England)

# Specific patient group covered

Adults (aged 19 and over) with diagnosed HIV infection requiring ongoing specialised HIV services. Whilst adult services are generally defined as for those aged 19 and over, it is likely that adult services may treat some patients aged 15 – 18 because of the specific needs of the individual patient. Some adult services will deliver transition services for children and young people with HIV. This will be done in collaboration with paediatric services and in line with service specification B6b.

HIV is an open access service and adults with diagnosed HIV can self referral. Any service diagnosing HIV infection in adults can also refer to any HIV specialised service provider. This ensures equity of access.

Specialised HIV services will also be provided to adults in prisons, in custody and in immigration detention. These may be provided on an in-reach or outpatient / inpatient basis and this will be reflected in the relevant specification for offender health.

UK treatment guidelines recommend initiation of treatment at CD4 of 350. Where clinically indicated, initiation at CD4 of 500 or over may be appropriate. It is anticipated that during 2013/14, the HIV CRG will provide advice to NHS England in its consideration of a commissioning policy for Treatment as Prevention (treatment of HIV positive adults irrespective of CD4 count) which will result in earlier initiation of treatment for the primary purpose of reducing HIV transmission risk.

# 2.4 Any acceptance and exclusion criteria

## Acceptance criteria

The service will accept inward referrals from:

- HIV positive adults on a self referral basis.
- Sexual health and reproductive health services.
- Primary care.
- All other services undertaking HIV testing.
- All specialities where an HIV diagnosis has been made including emergency care
- Paediatric HIV services.
- Other specialised HIV services.

The service will accept referrals for patients who meet the following criteria

Diagnosed as HIV positive.

All eligible patients will have access to care and treatment services irrespective of their sexual orientation, gender, race, disability or geographical location.

On receipt of referrals, the specialised HIV outpatient service will assign a named HIV consultant for the management of the patient. Following assessment, the case management approach may involve other members of the MDT taking an active role in coordinating the care of the patient.

# Discharge and exit criteria

Adults with HIV accessing outpatient care are unlikely to be discharged as they will require ongoing care and treatment. Discharge will only occur where

- Patients transfer their care between specialised HIV care providers or where shared care arrangements are in place. Patients notes to be transferred within 2 weeks of referral.
- Patients become lost to follow up. Services will need to have a policy to demonstrate how they aim to ensure retention in care and when patients are considered discharged.
- Adults with HIV who have other health needs which require management by other

clinical specialties or services can expect to be referred for these elements of service.

A patient leaves the UK or dies.

In specialised HIV inpatient care, discharge as per needs of the individual patient and effective discharge planning arrangements being in place.

A number of inpatients will be diagnosed with HIV during their admission. To avoid patients being lost to follow up in HIV care, the inpatient provider will ensure the patient is linked to an HIV outpatient service and discharged with the appropriate support for adherence.

#### **Exclusions**

The following are excluded from the specialised HIV service for adults:

- Children: Service specification B6b sets out requirements for specialised paediatric HIV care. It is likely that adult services may treat some patients aged 15 18 either because transition is occurring before 19 years of age and transition services are offered in conjunction with the paediatric service or because of the specific needs of the individual patient. This is acceptable ensuring that appropriate links are made with paediatric services. Patients under the age of 15 shall be referred to paediatric services for care.
- Non HIV care needs of adult HIV patient For the general population, consultant referral is via a GP. Historically in HIV, referrals to other specialties were made via the HIV consultant. Whilst there may be some scenarios where urgent consultant to consultant referral is appropriate, it is unlikely that this will be generally the case. In 2013/14, the HIV Clinical Reference Group, BHIVA and the RCGPs will produce recommendations for defining shared care responsibilities between primary care and HIV specialised services. This will include proposing appropriate consultant to consultant referrals and ensuring that by more effective involvement of primary care adults with HIV do not experience poorer health outcomes compared to the general population.
- Whilst NHS England will commission all ARVs (including their use as Post Exposure Prophylaxis to prevent HIV infection), it does not commission prevention services. Also excluded is prescribing of ARVs for Pre exposure Prophylaxis. Providers must ensure pharmacy systems can record use of ARVs for prevention, hepatitis and HIV separately. HIV prevention is commissioned and funded by Local Authorities and / or Clinical Commissioning Groups and must be invoiced to the appropriate commissioner accordingly. Note: As PrEP is not a licensed treatment in the UK, has not been evaluated by UK regulatory authorities or NICE and has not been agreed be commissioners, it shall not be provided outside clinical trials.
- Prescribing of ARVs for hepatitis this will be commissioned as part of the Infectious Diseases specification.
- HIV testing many specialised HIV service providers may also provide sexual health services including HIV testing and STI screening. Whilst these services are part of an HIV pathway of care they are commissioned by Local Authorities.

- ARV prescribing which is not in line with commissioning policies agreed with commissioners. In the absence of NICE guidance, commissioners will work with clinicians and patients to agree high quality prescribing arrangements informed by BHIVA guidelines and which deliver cost effectiveness. Prescribing outside of these arrangements (e.g. agreed formulary arrangements, drug procurement frameworks, home delivery arrangements) will not be funded.
- HIV treatment and care provided through clinical trials Payment for ARVs or any additional or excess treatment costs associated with research trials.
   Commissioners are not required to continue funding treatments at the end of clinical trials. Entry / exit arrangements for all trials / research programmes shall be agreed with commissioners in advance.
- New treatments / ARVs until approved by commissioners.
- Any other activity not covered in the specification must be raised by the provider with the commissioner for prior approval and written confirmation provided by the commissioner that this will be funded.

## 2.5 Interdependencies with other services

### **Co-located services**

For HIV outpatient care, there are no essential service co-location requirements.

For HIV inpatient care, co-location requirements as recommended in the BHIVA Standards of Care 2013 include the following:

- Provision of 24-hour access for acute care.
- Co-location with HDU and ITU services with appropriate escalation of care to HDU and ITU when indicated.
- Full range of imaging services.
- 24-hour availability of pharmacy services and access to specialist HIV pharmacist advice.

### Interdependent services

For HIV outpatient care, the interdependent service requirements include:

- Sexual health and reproductive health services.
- Primary care.
- A full range of diagnostic imaging and pathology services.
- HIV virology including interpretation of resistance patterns.
- Access to dietetics, physiotherapy, occupational therapy and clinical psychology.
- Third sector services to support adherence, peer support and self-management programmes.
- Specialised HIV Services for Children.

For HIV inpatient care, the interdependent service requirements include direct access to, and close liaison with, the following related services:

- Sexual health and reproductive health services
- Primary care

- Endocrinology
- Oncology
- Infectious Diseases (TB / HPV / Hepatitis)
- Renal medicine
- Haematology/haemato-oncology
- Dermatology
- Otorhinolaryngology
- Gastroenterology, especially endoscopy
- Lipid, hypertension and cardiovascular medicine
- A full range of diagnostic imaging and pathology services
- HIV virology including interpretation of resistance patterns
- Ophthalmology
- Dental/oral medicine
- Dietetics, physiotherapy, occupational therapy and clinical psychology
- Obstetrics and gynaecology including liaison midwifery, subfertility and colposcopy
- Access to bone marrow transplantation (for lymphoma patients)
- Access to plastic surgery for lipodystrophy
- Specialised HIV Services for Children
- Palliative care medicine
- Mental health services for patients with significant mental health needs ranging from third sector support service to clinical psychology and liaison psychiatry and liaison with community mental health services in patients' place of residence.
- Third sector services to support adherence, peer support and self-management programmes.

#### Related services

The effectiveness of specialised HIV services depends on other elements of the HIV pathway being in place and effectively coordinated. In addition to the services listed as 'interdependent', agreed referral pathways will be required with the following services in order that the Specialised HIV services can deliver the aims and objectives of the service and deliver a seamless pathway of care for patients:

- Third sector HIV care and support services for treatment adherence, peer support and self management.
- Social care, mental health and community services for rehabilitation, personal care or housing.
- End of life care.

Specialised HIV Services contribute to HIV prevention through support to individuals to improve their own health and to reduce the risk of onward transmission of HIV infection. Effective HIV services can reduce mortality and morbidity not only in relation to HIV but also other co morbidities which can disproportionately affect adults with HIV.

For HIV patients with other health conditions, agreed pathways for referral to quaternary and supra-regional services including:

- Liver and renal transplantation.
- Therapeutic drug monitoring and its interpretation.
- Specialist management of multi-drug resistant TB.
- Specialist histo /cytopathology via referral access to appropriate experts for diagnostic advice on difficult cases.
- HIV autopsy service with an interested pathologist who takes part in mortality meetings with the clinical team, if not available within the HIV centre itself.

## 2.6 Currencies and coding

For outpatient services, a national PbR tariff is in development. This is proposed as a year of care tariff with currencies of new, stable and complex patients. Coding and payment will be dependent on full and timely submission of quarterly data to Public Health England of the new HARS dataset.

For inpatient care, activity is to be identified through clinical coding where HIV is identified as the primary diagnosis.

As ARVs are PbR excluded drugs, providers must report spend with reference to patients covered and exclusions set out in this specification.

# 3. Applicable Service Standards

# 3.1 Applicable national standards e.g. NICE, Royal College

Whilst all applicable standards and guidelines are set out in section 1 - Key Documents / Evidence base, of particular note are:

- The BHIVA Standards of Care for People Living with HIV in 2013. These have been endorsed by the HIV CRG
- http://www.bhiva.org/standards-of-care-2013.aspx
- Standards for psychological support for adults living with HIV, 2011 British Psychological Society in association with BHIVA and Medfash <a href="http://www.medfash.org.uk/uploads/files/p17abjjlhe7as89k45i1icg1f121.pdf">http://www.medfash.org.uk/uploads/files/p17abjjlhe7as89k45i1icg1f121.pdf</a>
- The British HIV Association is the professional body for HIV. Following assessment of its process for consideration of clinical evidence, BHIVA has been accredited as a guideline writing organisation by NICE from 2012.

### 4. Key Service Outcomes

#### 4.1 Overview of outcome measures

HIV specialised service (outpatients and inpatients) will support reduced mortality, improved morbidity, improved patient experience and reduced HIV transmission in adults with HIV. Delivery of these outcomes will be measured through

- CQUIN measures advised by the HIV CRG
- Quality dashboard indicators advised by the HIV CRG
- Public Health Outcome measures (reduced late diagnosis)
- Other key performance indicators as appropriate

Measurement of outcomes will rely on complete data reporting to HIV surveillance systems. In addition, some outcome measures will be reported on an annual, quarterly or monthly basis to commissioners as per contract requirements. The measures set out here will be further specified in line with auditable outcome measures agreed through relevant Standards and Guidelines. These are likely to be subject to annual review in order to ensure outcome measures reflect any changes in clinical practice or commissioning requirements.

#### **CQUIN** measures

CQUIN measures will include:

engagement and communication with GPs

# **Quality dashboard measures**

The quality dashboard will benchmark services largely using surveillance data. The measures relate to:

- Domain 1: Preventing people from dying prematurely
- Domain 3: Helping people to recover from episodes of ill health or following injury
- Domain 4: Ensuring that people have a positive experience of care

### **Key Performance indicators**

Key performance indicators will reflect the BHIVA Standards 2013 and will include process measures which are a proxy for the quality of outcome to be achieved including:

- Speed of access into care following diagnosis.
- Retention in care and documented protocols.
- Suitably qualified MDT with evidence of qualification and CPD.
- Facilities and co-location of services.
- Documentation of patient baseline results.
- Documented care plans with patient involvement.
- Documented adherence support and medicines review.
- Improvement in the patient experience of individuals with HIV infection attending HIV outpatient service and improvement in reported understanding / self management of their condition.

- Reporting and audit.
- Care and treatment to professional guidelines and commissioning policies.
- Reductions in complications in complications of HIV disease including AIDS and non AIDS co-morbidities.
- Reduction in treatment associated complications and development of drug resistance.
- Improved treatment adherence.
- Effectiveness of networked arrangements and documented pathways.
- Reduction in the proportion of patients lost to follow up and in do not attend rates
- Improvement in the reported psychological, emotional and cognitive well being of people living with HIV infection.
- Reduction in the potential for onward transmission.
- Implementation of electronic patient records
- Documented health screens e.g. 10-year cardiovascular disease (CVD) risk, smoking, psychological needs, and appropriate referral.
- Time to admission / transfer for inpatient care.