Providing for the needs of people with HIV/AIDS in Wales

National Care Pathways and Service Specification for testing, diagnosis, treatment and supportive care

August 2009
## Contents

1. Executive Summary 1  
2. Background 2  
3. Methodology and Literature search 5  
4. Quality requirements for HIV and AIDs 6  
5. The care pathway 8  
   5.1 Care pathway for adults 8  
   5.2 Clinical case management of adults 9  
   5.3 Clinical care pathway for pregnant women 10  
   5.4 Care pathway for children 11  
   5.5 Social and supportive care pathway 12  
6. Service specification for HIV care 13  
   6.1 Testing 13  
   6.2 Testing infants and young children 15  
   6.3 Diagnosis 16  
   6.4 Assessment after diagnosis 19  
   6.5 Patient education and shared decision making 20  
   6.6 First line HAART therapy 20  
   6.7 Patient monitoring 21  
   6.8 Failure of HAART and HIV drug resistance 21  
   6.9 Ongoing HIV care and support 21  
   6.10 Sexual and reproductive health 22  
   6.11 Non HIV related health care and primary care 23  
   6.12 Pregnancy and perinatal care 23  
   6.13 Paediatric HIV care 24  
   6.14 HIV care for prisoners, IDUs and sex workers 26  
   6.15 Supportive care 26  
   6.16 Palliative care 27  
   6.17 Social care 27  
   6.18 Post exposure prophylaxis 28  
7. Clinical Networks 30  
8. Service components and outcome indicators 35  

## Appendices

1. Membership and terms of reference of task and finish group 44  
2. Source documents 46  
3. Glossary of abbreviations 48
1. Executive Summary

This service specification documents the recommended models of care for patients with HIV or AIDS – it includes the following services:

- Specialist Clinical Services for HIV positive patients.
- Supporting clinical services, including: sexual health; obstetric services; fertility services; mental health and psychological care services.
- Voluntary organisations.
- Social care and welfare advice services for people with HIV and members of affected groups, including asylum seekers and other migrants.
- Services for families affected by HIV, including but not confined to specialist paediatric care for children and adolescents with HIV and transition from adolescent into adult services.
- Drug and alcohol services.
- Services for prisoners and detainees, commercial sex workers.

HIV is a complex, incurable, chronic medical condition but the morbidity and mortality related to HIV can be considerably reduced by effective monitoring and treatment. This service specification is based on that of other such conditions in line with Welsh Assembly Guidance, designed to Improve Health and the Management of Chronic Conditions in Wales.

Primary care medical and dental services will continue to provide for the general health needs of HIV positive individuals.

The specification, however, recognises the stigma that remains associated with HIV infection and the need for partnership working across agencies.

Effective management of HIV requires the provision of a comprehensive care programme delivered by a multidisciplinary team.

Each individual living with HIV has unique demands and an appropriate package of care for any one individual will require input from both the voluntary and statutory sector.

The service specification builds on the HIV/AIDS quality requirements published in the Sexual Health Quality Requirements for Wales.
2. Background

Human immunodeficiency virus (HIV) is one of the most important communicable diseases in the UK. HIV is a lifelong and potentially fatal condition. HIV infection has a major impact on lifestyle, relationships, work, health wellbeing and life expectancy. The virus affects a broad cross section of members of society in terms of age, gender, sexual orientation and socio-economic status. In Wales there were 1,009 individuals accessing treatment for HIV at the end of December 2007. The advent of highly active antiretroviral therapy (HAART) since 1995 has resulted in HIV infection becoming more controlled and managed as chronic disease. For many of those infected this has resulted in return to health or delay in the onset of illness. Treatment is complex and has potential side effects. Not all those infected with HIV respond favourably to treatment and these individuals will require additional support from a range of service providers.

Table 1 – Number of HIV Positive Individuals, resident in Wales, treated in clinics 1997 – 2007

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV positive individuals</td>
<td>223</td>
<td>256</td>
<td>288</td>
<td>308</td>
<td>380</td>
<td>419</td>
<td>575</td>
<td>676</td>
<td>759</td>
<td>884</td>
<td>1009</td>
</tr>
</tbody>
</table>

The number of individuals with HIV infection who are cared for by services in Wales is increasing year on year with consequent decrease in the new to follow up ratio.

Each and every individual living with HIV requires specialist long-term clinical supervision and support for HIV.

The success of HAART therapy means that patients are living longer and over time will develop medical and surgical needs associated with increasing age. Inevitably this will mean that general health service will become more involved with their care.

Over the past decade there has been a rapid increase in the number of HIV infections diagnosed in Wales which were acquired through heterosexual sex (see Figure 1). Of these the majority were acquired abroad. In the UK as a whole we are seeing small but increasing numbers of people diagnosed with HIV infection who do not have any history of exposure to known high risk event or partner.
There has been effective treatment for HIV since the mid 1990s. Antiretroviral therapy (ART) and other interventions have resulted in the dramatic reduction in the number of HIV related deaths in Wales and most infected people in Wales are living with HIV as a chronic condition rather than an inevitably fatal illness.

### Table 2 – Stage of Disease & Drug Therapy 2007/2008

<table>
<thead>
<tr>
<th>Stage of Disease</th>
<th>Number of Patients</th>
<th>Number Receiving Antiretroviral Therapy</th>
<th>Percentage Receiving Antiretroviral Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asymptomatic</td>
<td>366</td>
<td>181</td>
<td>49.4%</td>
</tr>
<tr>
<td>Symptomatic</td>
<td>340</td>
<td>297</td>
<td>87.4%</td>
</tr>
<tr>
<td>AIDS</td>
<td>188</td>
<td>177</td>
<td>94.1%</td>
</tr>
<tr>
<td>AIDS Related</td>
<td>3</td>
<td>2</td>
<td>66.6%</td>
</tr>
</tbody>
</table>

In the calendar year 2007 there were 198 cases of AIDS recorded in individuals living with HIV in Wales. There were also 3 deaths in individuals with AIDS and 1 death in an individual who was HIV positive but who did not have an AIDS defining illness.

HIV care is provided in 8 hospitals in Wales, 7 of these are tertiary sexual health clinics and one an Infectious disease unit.
Table 3: Care providers in Wales and activity data from 2003 – 2007

<table>
<thead>
<tr>
<th>Site of treatment</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>Swansea - Singleton Hospital</td>
<td>115</td>
<td>139</td>
<td>171</td>
<td>192</td>
<td>208</td>
</tr>
<tr>
<td>Bangor - Ysbyty Gwynedd Hospital</td>
<td>29</td>
<td>32</td>
<td>29</td>
<td>39</td>
<td>45</td>
</tr>
<tr>
<td>Bodelwyddan - Ysbyty Glan Clwyd</td>
<td>27</td>
<td>36</td>
<td>47</td>
<td>53</td>
<td>55</td>
</tr>
<tr>
<td>Wrexham - Ysbyty Maelor Hospital</td>
<td>29</td>
<td>28</td>
<td>33</td>
<td>40</td>
<td>47</td>
</tr>
<tr>
<td>Cardiff - Royal Infirmary</td>
<td>183</td>
<td>207</td>
<td>222</td>
<td>260</td>
<td>311</td>
</tr>
<tr>
<td>Cardiff - University Hospital of Wales</td>
<td>99</td>
<td>106</td>
<td>121</td>
<td>132</td>
<td>136</td>
</tr>
<tr>
<td>Llantrisant - Royal Glamorgan General</td>
<td>21</td>
<td>26</td>
<td>30</td>
<td>52</td>
<td>49</td>
</tr>
<tr>
<td>Newport - Royal Gwent Hospital</td>
<td>32</td>
<td>42</td>
<td>49</td>
<td>60</td>
<td>86</td>
</tr>
<tr>
<td>Total</td>
<td>535</td>
<td>616</td>
<td>702</td>
<td>828</td>
<td>937</td>
</tr>
</tbody>
</table>

In 2007/08 services were provided for 15 HIV positive children in Wales and, as of March 2007, there were 14 HIV indeterminate babies.

As can be seen in Table 4, 54% of people with newly diagnosed HIV in S E Wales are diagnosed at a late stage in the illness and have a CD4 count of 350 or less. This late presentation is seen across the UK. This delay in diagnosis results in: a worse prognosis with significantly increased risk of permanent disability; a significant increase in mortality and ongoing transmission to sexual partners. Many clinicians still believe that discussing HIV with patients is difficult and that patients need “pre-test counselling” by a trained counsellor. This approach is a legacy of a time when the prognosis for those infected with HIV was poor and treatment options were limited.
3. Methodology and literature search

3.1 Multidisciplinary Input

The service specification and care pathways have been written by members of a Task and Finish group (membership and terms of reference Appendix1). Membership of the group included representation from: BASHH Wales; BHIVA; adult and paediatric infectious diseases; Office of the Chief Medical Officer, WAG; National Public Health Service, Wales; Antenatal Screening Programme, Wales; Terrence Higgins Trust; Local Authorities, Wales; and GPC Wales.

3.2 Literature Search

Where possible recommendations in the specification are related directly to formal levels of published evidence and guidance (Appendix 2).

Literature searches on Medline were carried out to identify any existing service specifications, protocols or care pathways related to the delivery of care and support to those affected by HIV/AIDS. The following key words were used: HIV/AIDS; service specification; care pathway; social care; supportive care; palliative care; antenatal testing; point of care testing.
4. Quality Requirements for HIV/AIDS

Each patient with HIV and their carers and families have access to specialist HIV treatment and care services and those requiring multiagency support receive integrated care.

Aim: To ensure all people with HIV, their carers and families have access to specialist HIV treatment and care services that meet their needs and that those requiring multi-agency support receive integrated care.

Peoples experience:

The individual should have:

- Access to HIV testing in both primary and secondary care services, irrespective of age, gender, ethnicity and sexual orientation if they are sexually active.
- An assessment by specialist HIV clinical staff within 2 weeks of HIV diagnosis.
- Joint decision making with providers of services.
- Access to specialist HIV treatment and care services; to a full range of medical specialties and supporting services, both in community and/or secondary care.
- Access to good quality medical and dental care.
- Access to support for secondary prevention in relation to sex, relationships and disclosure.
- Access to social care services which are responsive, culturally appropriate and tailored to individual need.
- Integrated sexual health and HIV care.
- 24 hour emergency care provided for all emergencies (HIV and other) including post exposure prophylaxis for non occupational HIV exposure.
- Access to palliative and respite care services.
- All women in Wales will be offered the HIV screening in pregnancy as recommended in Antenatal Screening Wales (ASW) Policy and Standards (2005) and if positive, will receive appropriate integrated care in accordance with BHIVA guidance.
- Children, their families and carers will have access to both specialist adult and paediatric multidisciplinary care and support.

Services Provided

- Within 2 weeks of HIV diagnosis, all patients should have an appointment for assessment by specialist clinical HIV staff.
- Specialist HIV services provided, as a minimum, in closely monitored clinical networks, which may require amalgamation into tertiary centres.
- Services reflect formal patient involvement to ensure constructive dialogue between clinics and people with HIV.
- Through the clinical networks, resources to support medical and
dental care will be identified and allocated such that appropriate care pathways can be developed.

- Each network will be developed to support integrated care, all agencies that contribute to this will be involved and roles and responsibilities clearly defined and understood.
- Each network should ensure services provided within their area are consistent with the BHIVA: Standards for HIV Clinical Care (see section 7).
- Where needed, patients and their carers should have access to supportive, respite and palliative care in accordance with The All Wales Care Pathway for the Last Days of Life.
5. The Care Pathway

5.1 HIV Care pathway - adults

- Self Referral
- Voluntary sector
- GP/Hospital Social care

- Initial Assessment after diagnosis

- Full Assessment

- Care Plan

- Intervention

- Review

- External Referral

- Self Management e.g. EPP

- Case Management

- Advice Service

- Counselling + Emotional Support

- Community Support

- Case Management

Health Promotion
(Opportunities for health promotion interventions are taken up wherever they occur)
5.2 The Clinical Case Management of Non-Pregnant HIV Positive Adults

Assessment after diagnosis by specialist HIV

Patient education and shared decision making

Clinical Assessment and care plan

HAART not indicated

Monitoring

Indication for HAART

Initiation of HAART

Monitoring

Failure of HAART/HIV drug resistance

Primary care and dental care

Interventions

Supportive and social care

Palliative care

Sexual & reproductive health

Management of co-infection and HIV related illness
5.3. Clinical care pathway for pregnant women

- **Known HIV infected woman**
  - Medical care
    - Pregnancy
      - HIV Positive Pregnant Woman
        - Multidisciplinary care: obstetrician, paediatrician, HIV physician, etc
        - Informed decision making by mother, plan developed for MTCT prevention and HIV disease management
  - Recommend and educate against breast feeding
  - Full implementation of HAART
  - Delivery plan according to guidelines

- **Pregnant woman of unknown HIV**
  - Planned Antenatal care
    - Universal HIV Testing
      - Positive
      - Presentation at labour
      - Presentation after delivery and within 48hrs
    - Unplanned late presentation
      - Rapid HIV test offered
      - Positive
    - Counselling on family planning – contraceptive and preconceptual advice
5.4 HIV Care pathway - paediatrics

- Antenatal care referral
- Antenatal care birth care plan
- Maternal antibodies Start ART for 4 weeks
- Retest at 4 weeks and three months
- Discharge at 24 months if no antibodies detected
- Assessment within 4 hours
- External Referral-shared care
- Multidisciplinary Care Plan
- Interventions
- Review
- Advice Service
- Counselling + Emotional Support
- Community Support

- Late referral in labour
- Rapid testing of maternal bloods/POCT
- Evidence of proviral infection Start ART

- Child diagnosed HIV positive as result of symptoms
- Full Assessment

- Child of HIV positive parent
- Initial Assessment
- Full Assessment
5.5 Social and Supportive Care
6. **Service Specification for integrated health and social care**

The needs of people with HIV infection are different now to when services were first established over 20 years ago. HIV is now a complex, chronic medical condition and this model of care is based on that of other such conditions.

The advent of highly active anti-retroviral therapy (HAART) and the challenges for patients now are much more about maintaining a good quality of life, helping them to adjust to their diagnosis, empowerment, increasing self-esteem, and living with a chronic illness.

Many with HIV infection will require little support while a few may require a considerable amount. The range of services necessary for HIV care and management included in the service specification are:

1. Specialist Clinical Services for HIV positive patients.
2. Supporting clinical services, including: sexual health; obstetric services; fertility services; mental health and psychological care services.
3. Voluntary organisations.
4. Social care and welfare advice services for people with HIV and members of affected groups, including asylum seekers and other migrants.
5. Services for families affected by HIV, including but not confined to specialist paediatric care for children and adolescents with HIV and transition from adolescent into adult services.
6. Drug and alcohol services.
7. Services for prisoners and detainees, commercial sex workers.

6.1 **Testing for HIV infection (UK national guidelines for HIV testing 2008)**

- Patients should be offered and encouraged to accept the HIV test in a wide range of settings.
- Patients with specific indicator conditions should be routinely recommended to have an HIV test.
- All doctors, nurses and midwives should be able to obtain informed consent for an HIV test in the same way that they currently do any other medical investigation. The essential elements of pre-test discussion should cover:
  - The benefits of testing to the individual.
  - Details of how the test results will be communicated and should include awareness of the window period.
- Opt out HIV testing should be provided in all tertiary sexual health services.
- It is good practice to offer a HIV test to all those who present with:
  - Tuberculosis.
  - Hepatitis C.
• The general principles of confidentiality should be followed as laid down by the GMC in its guidance *Confidentiality: protecting and providing information*.

• The results of an HIV test (if positive) should be given directly by the testing clinician (or team) to the patient and not to any third party, including relatives or other clinical team unless the patient has specifically agreed to this.

• **Universal HIV testing** is recommended in the following settings:
  
  • GUM/ sexual health clinics (tertiary services) – opt out testing.
  • Antenatal services (Currently in Wales HIV testing is offered to all pregnant women. Antenatal Screening Services, Wales will review their current policy in the light of recent UK guidance and the recommendations of UK Antenatal Screening Committee guidance due in March 2009.
  • Termination of pregnancy services.
  • Drug dependency programmes.
  • Health care services for those diagnosed with:
    
    • TB.
    • Hepatitis B/C.
    • Lymphomas.
    • Unexplained lymphopaenia/ thrombocytopaenia.
    • Unexplained fever, weight loss and night sweats.
    • Oral candidiasis/ oral hairy leukoplakia.
    • History of shingles (especially in multiple dermatomes).
    • Unexplained lymphadenopathy.
    • Recurrent pneumonia.
    • All men and women known to be from a country of high HIV prevalence (≥1%). Up to date list available at: [http://www.unaids.org/en/KnowledgeCentre/HIVData/Epidemiology/latestEpiDataasp](http://www.unaids.org/en/KnowledgeCentre/HIVData/Epidemiology/latestEpiDataasp).

• **HIV testing should be routinely offered** and recommended to the following patients:
  
  • All patients where HIV, including primary HIV infection, enter the differential diagnoses.
  • All patients diagnosed with STI.
  • All sexual partners of men and women known to be HIV positive.
  • All men who have disclosed sexual contact with other men.
  • All female sexual contacts of men who have sex with men.
  • All patients reporting a history of injecting drug use.
• **Department of Health guidance** – HIV routinely performed on:
  - Blood donors.
  - Dialysis patients.
  - Organ transplant donors.

• **Annual tests should be offered to:**
  - Men who have sex with men - HIV testing may be offered more frequently if clinical symptoms are suggestive of sero-conversion or there is ongoing high risk of exposure.
  - Intravenous drug users - HIV testing may be offered more frequently if indicated.

Antenatal care: Women presenting for the first time to services in labour should be offered an urgent test which may, if previously agreed locally, be delivered by point of care test (POCT).

6.2 **Testing Infants and young children**

• Any infant/child/young person thought to be at significant risk of HIV infection, including all those with parents or siblings, who are HIV-infected, should be tested. It is in the best interest of the infant / child/young person to be tested in these circumstances although this only needs to be undertaken urgently in infants who are at risk of rapid disease progression.

Who to consider for HIV testing

• Infants and children whatever their age where the mother has HIV, or may have died of an HIV-associated condition.
• Infants born to mothers known to have HIV in pregnancy.
• Infants born to mothers who have refused an HIV test in pregnancy.
• Infants and children who are presented for fostering/adoption where there is any risk of blood-borne infections.
• Infants and children newly arrived in the UK from high-prevalence areas (they may be unaccompanied minors).
• Infants and children with signs and symptoms consistent with an HIV diagnosis.
• Infants and children being screened for a congenital immunodeficiency.
• Infants and children requiring post-exposure prophylaxis.
• Infants and children in cases where there has been sexual abuse (see below).

Obtaining consent for HIV testing from children

In Wales, children are defined as those under 18 years old (Children Act 1989). Under English law young people aged 16 years or over are assumed to have the capacity to consent to medical treatment and should be
treated in the same way as adults. Young people under 16 years accessing sexual healthcare (which would include HIV testing as part of a sexual health screen) without a parent or guardian should be assessed for competency to consent.

**Testing in a non-competent child**

If a child lacks the capacity to consent, then the consent of one parent or carer with parental responsibility is sufficient. As most children with HIV will have acquired their illness from their mother, the involvement and consent of the mother should ideally be sought but it is good practice to involve both parents. If you are aware of parental disagreement, refer to GMC guidance.

**Refusal of testing by a competent young person**

The Children Act (1989) promotes the participation of children in giving consent to procedures and their involvement in the discussions on testing should be encouraged where appropriate. The law on parents overriding a competent young person’s refusal to testing is complex. Legal advice should be sought about whether to apply to the court if testing is thought to be in the best interest of a competent child who refuses.

**Testing looked after children**

For children looked after by social services, parental responsibility may be shared between the parents and local authority. Many local authorities have developed their own policies around testing of children and these should be referred to. They often involve consent having to be given by the Director or Assistant Director of social services and this should be obtained in writing. It is still important to consider the implications for the birth parents, particularly the mother as a positive test may mean that she also has HIV and it is important to consider how this will be handled. If a child is a ward of court only the court can make major decisions affecting the child.

### 6.3 Diagnosis

**What test?**

There are three methods acceptable for diagnosing HIV infection:

- Blood tests.
- POCTs.
- Dried Blood Spot (DBS).

#### 6.3.1 Blood Tests

The recommended first-line assay is one which tests for HIV antibody AND p24 antigen simultaneously.
• All primary screening laboratories must offer an HIV screening test which detects both antibody AND p24 antigen.

• There is a requirement for three independent assays to confirm diagnosis followed by another test which is able to distinguish HIV-1 from HIV-2. These tests should be provided within the primary testing laboratory, or by a referral laboratory.

• All new HIV diagnoses should be made only after completing appropriate confirmatory assays and testing a second sample.

6.3.2 POCT

POCTs offer the advantages of a result either from a finger prick/mouth swab within minutes. POCTs have reduced sensitivity and specificity when compared to 4th generation laboratory tests.

• Because of the low specificity and resulting poor positive predictive value all positive results must be confirmed by serological tests as there will be false positives, particularly in lower prevalence environments.

• Only CE-marked POCT kits should be used and a nominated accredited pathology laboratory should assist with governance issues and quality assurance of the tertiary process.

• POCT has value in community settings and in certain clinical settings where a rapid test result (within one hour) from the local laboratory cannot be guaranteed. Such clinical settings may include:
  • GUM clinics.
  • Obstetric settings for high risk patients.
  • Source patient testing prior to post-exposure prophylaxis (PEP) for both occupational and sexual exposure.
  • Individuals presenting for post-exposure prophylaxis following sexual exposure to prevent inadvertent and unplanned treatment of undiagnosed HIV infection.

• All HIV units must develop local plans for ensuring access to rapid testing. Where a guarantee of a test result being available from the local laboratory within an hour is problematic, the network could consider meeting this need by collaborating with the local microbiology laboratory in training staff and assuring that the service meets quality standards including those by MHRA, CPA and local Trusts all of which must have a POCT policy. POCT tests may be used in community clinics and outreach settings, particularly when providing a service for hard to reach groups but must be in collaboration with the local microbiology laboratory as above.
6.3.3 Dried Blood Spot

- Dried blood spot testing will be offered to intravenous drug users in a variety of settings once funding is assured.
- All positive tests will be followed up by serological tests.

Laboratory issues:

- All laboratories undertaking any diagnostic HIV services should be able to demonstrate satisfactory external quality control data for the tests undertaken and should have or be in the process of getting CPA accreditation.
- All laboratories must have arrangements for satisfactory HIV diagnostic confirmatory assays to be performed to allow timely definitive diagnoses. This may involve referring samples to specialist virology laboratory.
- All acute care settings should have access to an urgent HIV screening assay result within 24 hours and routine test results within 72 hours.
- Results should be available for the antenatal testing programme within 5 days.
- Laboratories must develop plans with local networks to ensure that HIV test results can be made available within the hour in exceptional clinical circumstances. This might be through the provision of and support for the delivery of a quality assured POCT.

Specialist laboratory requirements for on-going management of HIV positive patients:

- Virology.
- Immunology.
- Pharmacology.

Tests that may be requested include: Genotype Resistance Testing; Therapeutic Drug monitoring; HLA B5701 tissue typing; HIV Co-receptor Tropism Assay; Viral load monitoring and CD4 count.

Provision of test results:

- Face-to-face provision of HIV test results is strongly encouraged for:
  - Ward-based patients.
  - Patients more likely to have a HIV-positive result.
  - Those with mental health issues or risk of suicide.
  - Those for whom English is a second language.
  - Young people, 16 years.
  - Those who may be highly anxious/vulnerable.
Post-test discussion for those who are negative

- For those who are at higher risk of repeat exposure to the HIV infection offer health promotion screening for STI and advise around risk reduction or behaviour change including discussion relating to post-exposure prophylaxis (PEP). This is best achieved by onward referral to GUM/HIV services/voluntary sector services.
- The need for a repeat HIV test if still within the window period after a specific exposure should be discussed.

Post-test discussion for those who are positive

- Face-to-face, in a confidential environment and in a clear and direct manner. Consideration should be given to utilisation of an appropriate confidential translation service if required.
- Support should be available 24/7 for those with a new diagnosis.
- The clinician giving the results must have knowledge of local services and have established a clear pathway for onward referral.
- An individual testing HIV positive for the first time must be seen by a specialist (HIV clinician/specialist nurse/sexual health advisor/voluntary sector councillor) at the earliest opportunity, preferably within 48 hours and certainly within two weeks of receiving the results.

6.4 Assessment after diagnosis in HIV unit

- All patients should be assessed in a specialist HIV unit by a specialist doctor who provides HIV care within 2 weeks of a positive HIV test result, irrespective of the place of testing, unless the patient chooses to defer this.
- The specialist HIV doctor will operate as part of a multidisciplinary team, led by a consultant specialising in HIV care. Specialist medical staff will be supported at each outpatient clinic by:
  - A specialist HIV nurse.
  - A specialist pharmacist.
  - A specialist dietician.
  - A social worker.

and will have access by agreed referral process to support provided by:

- Voluntary sector (if not directly available in the clinic).
- Psychiatry and clinical psychology services.
- Obstetrician.
- Paediatrician.

- Arrangements for more rapid access must be in place for those with symptoms and/or particular needs or high levels of anxiety.
- In routine cases post-diagnosis assessment falls within the scope of outpatient HIV service.
• For newly diagnosed pregnant women the antenatal clinic may provide a more appropriate setting for initial assessment than the HIV unit or centre.
• If HIV is diagnosed during the course of an acute medical inpatient admission, advice must be sought immediately from a consultant qualified to provide HIV inpatient care. Consideration must be given to transferring the patient to the inpatient HIV centre.

6.5 Patient education and shared decision making

A diagnosis of HIV brings immediate information needs ranging from clinical questions about the infection and disease progression to psychological questions about transmission, discrimination, disclosure, service provision etc. Information needs will vary from individual to individual as will the ongoing extent for information needed by people with HIV, and will include topics such as the clinical impact of HIV, staying well and coping with illness, treatments, services and benefits, peer support, the law, employment and training, immigration and asylum, sex and sexual transmission, pregnancy and child-bearing etc. Information and support must be made available through a variety of interventions to meet the full range of HIV information needs.

• The process of involving patients and supporting shared decision-making about their individual care should start from the post-diagnosis assessment onwards and continue throughout the course of their HIV infection.
• It requires patient education and personalised information provision to be integrated as part of all HIV units and centre services, including delivery in partnership with community or voluntary providers.
• Culturally appropriate information on transmission, discrimination, disclosure and service provision must be available.
• All care must take place in partnership between people with HIV and care providers so that there is joint decision making and support to adopt a healthy lifestyle. Personal care plans should be developed.
• People who are HIV positive should be encouraged to become Expert Patients and courses to support this should be widely advertised.
• Culturally appropriate education, information and peer support should be offered.
• People who are HIV positive should be actively encouraged to participate in the Sexual Health Networks and to actively support the development of services that meets their needs.

6.6 First line HAART therapy

• Initiation of first-line HAART falls within the scope of outpatient HIV units and must be overseen by a Consultant, but arrangements must be made through clinical networks for 24-hour access to advice from a Consultant qualified to provide HIV care, typically via an HIV centre.
• Patients starting HAART for the first time must be given information on how to seek such advice if needed.
• Clinical networks should develop protocols for HAART initiation, including patient education and support and the appropriate choice of drugs.

6.7 Patient Monitoring

• Monitoring of patients with uncomplicated asymptomatic HIV infection, on or off HAART, forms part of Consultant led outpatient HIV unit services.
• This service must be supported by specialist pharmacist and dietitian.
• Access to specialist laboratory services is critical and must include access to: therapeutic drug monitoring; drug resistance testing; genotyping and tropism.
• Uncomplicated changes of HAART in patients with undetectable viral load and no history of drug resistance (e.g. for minor toxicity, patient choice or treatment simplification) form part of outpatient HIV unit services.
• Clinical networks should develop protocols for appropriate choice of therapy in such circumstances.

6.8 Failure of HAART and HIV drug resistance

• All patients who experience treatment failure (do not achieve or maintain virological suppression on HAART) should be reviewed regularly within the network to enable advice and input from HIV centre specialists.
• Ongoing care for these patients will usually fall within the scope of the outpatient HIV unit, but clinical networks should develop protocols for appropriate choices of therapy and for identification of more complex cases requiring joint assessment with the HIV centre before prescribing.
• The expertise of the specialist HIV pharmacist and specialist virologist will contribute to decision making process.
• All patients testing positive for HIV resistance to any HAART drug should be discussed jointly between HIV unit and HIV centre clinicians. Ongoing care will usually fall within the scope of the outpatient HIV unit, but advice should be sought from an HIV centre specialist for all subsequent changes in therapy for patients who have ever shown resistance to any HAART drug (including changes for toxicity in the absence of new resistance or failure).

6.9 Ongoing HIV care and support

Services for ongoing HIV care should include the following required provision:

• Case management for HIV as a long-term medical condition, with a focus on self-management and enabling adherence.
• Assessment and routine monitoring of HIV patients and initiation and monitoring of HAART in accordance with BHIVA and other relevant national and local guidelines.
• Asymptomatic patients should be monitored for the development of symptoms together with CD4 counts and viral loads.
• Antiretroviral therapy provided in accordance with BHIVA national guidelines and adequate support provided to ensure compliance with drug regimens.

• Access to specialist nursing within the local area.
• Specialist pharmacist support, either through local staff or via outreach from the HIV centre.
• Good links with mental health services with agreed referral pathways for psychology and psychiatric service.
• Appropriate laboratory services to support access to all relevant tests recommended in BHIVA guidelines for monitoring patients on and off HAART.
• Access to health advisor/counsellor as required.
• Access to peer support.
• 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.
• Facilities for partner notification.
• Health promotion services, provision of condoms and lubricants.
• GU/sexual health screening and services.

• Sexual health care must be integrated into the routine clinical practice of HIV units, including on-going risk assessment and screening for other blood borne viruses with appropriate immunisations offered.

• Access to contraception and pre-conception care.
• Cervical cytology for HIV positive women if indicated
• Clearly defined arrangements for network access to all HIV centre services including 24-hour advice.

Non-clinical aspects of these services may be delivered outside clinical settings and in partnership with a range of NHS and non-NHS providers, but there must be effective overseeing and co-ordination of multi-agency work to deliver the various service components, including clearly defined arrangements for liaison with generic and voluntary services.

6.10 Sexual and reproductive health of men and women living with HIV

• All HIV positive people undergoing follow up should have a sexual health assessment (every 6 months) and access to ongoing quality counselling and support.
• All HIV positive people undergoing follow up should be tested and treated for STIs if at risk.
• All HIV positive people undergoing follow up should be tested for hepatitis A, B and C at first presentation; vaccinated against hepatitis A and B if susceptible and subsequently should be tested annually for Hep B and C if they have exposure risk.
• PEP should be available and all HIV positive individuals should be aware of the units procedures.
• HIV positive men and women and their partners planning to have children should receive pre-conception counselling on all their conception options, including HIV transmission risk associated with each one so that they can make an informed choice.
• All newly diagnosed HIV positive women should have a sexual and gynaecological history as part of their initial assessment, including cytology and a sexual health screen if appropriate.
• All units should develop local policies and referral pathways for the management of suspected anal cancer and pre-cancer.

6.11 Non HIV related Health care and primary care

Primary care has particular strengths in areas which have become important as people with HIV disease live longer, eg cardiovascular disease prevention including smoking cessation, blood pressure and lipid management. Other examples include monitoring of renal function and treatment of mental health problems. Unlike primary care providers, most specialists in HIV medicine have little experience of elderly care, and will be ill-equipped to cope as increasing numbers of people with HIV reach old age and develop a range of co-morbid conditions and social care needs.

• The Non HIV related health needs of those who are infected with HIV should be managed by the same processes and referral pathways as for the general population this will become increasingly important with an ageing population of HIV infected individuals.
• Every patient with HIV infection must be strongly encouraged to register with a GP and involve him or her in their care.
• Patients should have a choice as to whether to receive treatment and care for their HIV infection in specialist settings only or whether to take part in shared care arrangements.
• At first consultation to discuss the positive result specialist staff must discuss disclosure with the HIV positive person so that there can be clarity around who needs to know and who does not need to know.
• Inevitably HIV positive people will have the same risk of developing the various types of dementia that an ageing population are susceptible to. These patients should be managed within existing expert services that have developed for the general population. (AIDS-related dementia, which is a consequence of uncontrolled HIV infection, should be treated by an HIV centre).

6.12 Pregnancy

All Welsh hospitals now have a policy to offer HIV testing to pregnant women. Untreated HIV infection in mothers results in HIV transmission to approximately 15-26% of infants, but transmission of HIV can be easily reduced to < 2% by a combination of interventions as per national guidelines. The evidence for these interventions and the possible scenarios are given in the BHIVA guidelines (http://www.bhiva.org), which should be referred to for cases which are not
straightforward, e.g. possible viral resistance, unsuppressed viral load, late presentation, or diagnosis at or after delivery.

- Normal pregnancy and delivery in women with uncomplicated HIV infection should ordinarily be managed within generic midwifery/obstetric services, with a named consultant obstetrician and paediatrician and support from HIV liaison midwifery. Provision of ART falls within the scope of the outpatient HIV unit but the birth plan and plans for paediatric care should be developed in consultation with the HIV centre and regional paediatric HIV clinic.
- An individual perinatal care plan should be available for all HIV-infected mothers.
- The care plan should be completed by the physician overseeing the management of HIV. It should be completed soon after anti-retroviral therapy has been started, and no later than 28 weeks (do not wait for the viral load to become undetectable). Copies of this care plan should be lodged in the following places:
  - HIV clinic records.
  - Obstetric notes.
  - Patient hand carried notes (if the patient is agreeable).
  - Labour ward.
  - Midwife.
  - Paediatrician.
  - Neonatologist.
  - GP (if the patient is agreeable).
  - Across each network area protocols should be agreed to ensure that.
  - In the event of a mother delivering unexpectedly in another hospital her HIV status will be known by the delivery team.

6.13 Paediatric HIV care

Children with vertically transmitted HIV first presented in the mid 80’s. The introduction of combination anti-retroviral therapy in the late 1990’s has been followed by a dramatic reduction in mortality. Infected children in the UK have become healthier and almost all are now surviving through adolescence and into adulthood. Over this time the management problems encountered by paediatricians have moved from treating sick young children to helping young people live as normal a life as possible with a chronic disease. The provision of services appropriate to adolescents with perinatally acquired HIV, and the managed transition of their care to adult services are increasingly important.

The care of HIV infection in children has become more complex, HIV should now only be managed in service networks with experts in this field, who are principally paediatric infectious disease specialists. It is proposed that expertise be developed at Cardiff and Vale Trust to provide the central focus for the provision of care to HIV positive children in South and Mid Wales. North Wales will continue to be supported by the Merseyside and Cheshire HIV network with referrals to and support provided by Alderhay Children’s Hospital.
The paediatrician will be directly supported by:

- A specialist paediatric HIV nurse.
- A specialist pharmacist.
- A specialist dietician a social worker.
- And by referral by other specialities.

**Diagnosis, baseline investigations, and pre-treatment monitoring**

- HIV diagnosis requires repeat positive PCR in infants and serology in older children.
- A detailed history of any possible previous antiretroviral therapy (ART) given to the child and/or mother (or other likely source of infection) should be documented.
- Drug history, viral resistance profile and HLA B*5701 type should be documented at baseline.
- Clinical assessment, CD4 count and viral load should be carried out 3-4 monthly in children who are stable off ART.
- Infants and older children who may need ART soon should be assessed more frequently.

**Prophylaxis against opportunistic infections**

- Prophylaxis against PCP should be given to all infants and to older children with low CD4 counts. Cotrimoxazole is the drug of first choice.
- No routine primary prophylaxis against other infections is recommended.
- Immunisation status should be checked, and boosted if required.

**When to start ART**

- ART should be started in all infants even if asymptomatic.
- ART should be started in all children with CDC stage B or C disease.
- ART should be started in asymptomatic older children based on age-specific CD4 counts.
- The aim of ART is to achieve an undetectable viral load (<50 copies/mL plasma) and CD4 reconstitution; VL and CD4 count should be monitored approximately every 3 months once established on ART.
- More frequent clinical and laboratory monitoring is required in infancy, if adherence is poor, soon after starting or changing therapy and when giving other medications such as anti-tuberculosis therapy.
- Switching treatment when there are ongoing problems with adherence may lead to loss of efficacy of further classes of ART.
- Where there are blips in VL, blood tests should be repeated to confirm significance.
- Resistance testing should be performed prior to switching regimens.
- Expert interpretation of resistance tests is required.
Adherence and disclosure

- Drug adherence is of paramount importance and should be discussed at each clinic visit.
- Disclosure to a child of their HIV diagnosis at the appropriate age should be promoted.

Stopping treatment and treatment interruptions

- Treatment interruptions cannot be recommended and starting ART currently means lifelong therapy.
- If stopping NNRTIs, this requires a substitution or staggered stop to reduce the risk of developing NNRTI resistance.

Co infections

- Hepatitis B and C both increase the risk of hepatotoxicity with ART.
- Drugs used to treat hepatitis B may select for resistant HIV virus and vice versa.
- There is significant interaction between ART and TB therapy. ART may be deferred at higher CD4 counts, or rifampicin and PIs may be avoided if low CD4 count necessitates simultaneous treatment; use of rifabutin can be considered.

6.14 HIV care for prisoners, intravenous drug users and sex workers

Specialist HIV services will develop referral pathways for the management of HIV infection in prison inmates, clients of drug misuse services and men and women working in the sex industry.

6.15 Supportive care

Supportive care providers will by agreement with LHBs:

- Ensure short term, evidence based individual and group support is available for people living with HIV and those that support and care for them at key points in the course of their condition, in order to enable them to live full and independent lives.
- Increase and improve access to mainstream health and social care services for people living with HIV.
- Increase access to HIV testing services for people at high risk of HIV.
- Provide meaningful and useful peer support and training to providers of health and social care services to ensure the services they provide are appropriate for HIV positive people and non-discriminatory.
- Promote self management by providing those living with HIV with the necessary supports to positively manage their own health and well-being.
- Ensure support and intervention is targeted so that populations that have higher risk of HIV, including men who have sex with men (MSM), and Black and Other Ethnic Minority communities have their needs met.
• Ensure Children and Young People living with and/or affected by HIV have access to child/youth appropriate support.

Ensure the range of services providing support and care to HIV positive people are well networked and co-ordinated and care pathways are in place (and agreed by providers) that clearly identify what services would provide intervention at the various points in the course of the target population’s condition.

6.16 Palliative care

• Mechanisms need to be established to ensure that each person approaching the end of life receives coordinated care, in accordance with an agreed care plan, across sectors and at all times.
• Each LHB area will need to assess the quantity and quality of care services in different settings. These will include services provided in hospitals, in the community, in care homes, sheltered and extra care housing, hospices and ambulance services.
• Working in partnership local care plans will be developed to include:
  • Discussions as the end of life approaches.
  • Assessment, care planning and review.
  • Coordination of care for individual patients.
  • Delivery of high quality services in different settings.
  • Care in the last days of life.
  • Care after death.

• Alongside all of these steps attention also needs to be given to:
  • Support for carers and families.
  • Information for patients and families.
  • Spiritual care for patients and families.

6.17 Social Care

Social care provided by local Authorities in Wales must be able to meet the complex and often acute needs of those living with HIV, in particular the needs of asylum seekers. They must be able to respond to specific needs around:

• Social care and support.
• Financial security.
• Education.
• Training and employment.
• Housing needs.
• Legal and welfare benefits.
• Immigration – referral to specialist legal services.
• Compliance with therapy.

The key aim is to enable those with HIV to remain independent for as long as they can and to help them and their carers to get information and support required in a simple and confidential way.
Each LA will have a nominated individual with knowledge of HIV and its implications for health and wellbeing. This individual to liaise closely with other providers of care both statutory and non-statutory.

All HIV positive individuals who request support will be provided with an initial assessment. Services provided will be based on the assessment findings and may include:

- Welfare rights and advice.
- Housing advice.
- Access to local services (drop-in/resource centres).
- Respite care.
- Emotional support and counselling.
- Access to charitable grants.
- Discharge planning.
- Crèche facilities etc.
- Information and advice.
- Signposting.
- Employment advice.
- Debt Advice.
- Advice re criminalisation concerns.
- Peer support.
- Education and training.

It is expected that Social services will respond within two days of receiving the referral and that the assessment process and provision of services will be completed in 28 days.

It is accepted that in some cases part or all of a clients social care needs will be best delivered via the voluntary sector.

6.18 Post exposure Prophylaxis

6.18.1 Occupational exposure

- LHBs must have arrangements in place for access to urgent advice about occupational exposure and PEP.
- A risk assessment needs to be made urgently by someone other than the exposed worker about the appropriateness of starting PEP, ideally a doctor designated according to local arrangements for the provision of urgent post-exposure advice.
- The issue of PEP should be considered after an exposure with the potential to transmit HIV, based on the type of body fluid or substance involved, and the route and severity of the exposure.
- The designated doctor or other practitioner should first assess if the exposure reported by the health care worker was significant – that is, with the potential to transmit HIV.
- If initial assessment indicates that an exposure has been significant - that is, with the potential for HIV transmission - consideration should then be
given to the HIV status of the source patient. It may be possible to ascertain from the medical record that a source patient has established HIV infection. Results from animal studies suggest that HIV PEP is most likely to be efficacious if started within the hour. An urgent preliminary risk assessment therefore should assess if it is appropriate to recommend that the exposed worker takes the first dose of PEP pending the outcome of a more thorough risk assessment to inform a decision whether to continue the regimen.

- The designated doctor should normally make arrangements to approach a source patient whose HIV status is not known and ask for their informed agreement to HIV testing.
- A universal approach to asking source patients to agree to have an HIV test avoids the need to make difficult judgements, simplifies and normalises the process and avoids the appearance of discrimination against people perceived as belonging to groups associated with higher than average HIV prevalence. However, there may be occasions when a preliminary risk assessment may be helpful in avoiding inappropriate HIV testing.
- When a source patient is asked to agree to be tested for HIV antibodies, careful pre-test discussion will be needed, as will informed consent. This pre-test discussion can be provided by any appropriately trained and competent health care worker. Specialist pre-test counselling may sometimes be considered appropriate if the circumstances of the source patient are unusual or complex.
- If there has been a significant exposure and a source patient cannot be identified, risk assessment should be on an individual basis. This will be informed by a consideration of the circumstances of the exposure, and the epidemiological likelihood of HIV in the source. In the vast majority of such exposures, it would be difficult to justify the use of PEP.

6.18.2 Non Occupational Exposure

- The use of PEPSE following potential sexual exposure to HIV is only recommended where the individual presents within 72 hours of exposure.
- Assessment and management of PEPSE should be in line with current guidelines.
7. Clinical Networks

It is essential that care across Wales is provided to the highest standard and that professionals are not isolated. The government accepts that to support this, individual service providers should work within a managed clinical network.

The initial view was that there should be a number of such networks organised on a regional basis across Wales, and that view is reflected in this document. However, the establishment of the new Local Health Boards (LHBs) from October 2009 may create bodies sufficiently large to manage these services directly.

In these circumstances the new LHBs should urgently review how to implement network arrangements – whether within their boundaries or on a regional basis. What is essential is that effective and sustainable services are made available to all, and the arrangements they choose will be rigorously assessed to ensure that that is the case.

Clinical care for diagnosed HIV infection in adult patients will be delivered through managed clinical networks each covering a defined geographical area and group of NHS organisations. Each network should have an identified consultant clinical lead and a network manager, with sufficient time and funding allocated for these to perform their respective network leadership roles.

The WAG Sexual Health Advisory Board will, through its HIV/AIDS Sub Group, provide the forum for:

- Supporting joint working between the three networks proposed for Wales.
- Providing guidance and leadership.
- Reviewing the service specification annually.
- Receiving reports on network activity as per outcome indicators.
- Supporting all Wales audit, research and training.

The following activities should be managed at the network level:

- Development and implementation of clinical and communication protocols and referral pathways.
- Continuing professional development regarding clinical aspects of HIV.
- Clinical audit related to HIV, including sharing of outcomes and action planning arising from the BHIVA national audit programme and other relevant national and local audit programmes.
- Public and patient involvement, including helping to design services.
- Planning of new service developments.
- Ensuring collaboration with HIV surveillance programmes managed by the Health Protection Agency and National Public Health Service for Wales.
- Linkage with the Children’s HIV National Network to ensure effective care for affected children, families and adolescents.
- Coordination of research including ensuring equitable access for eligible patients to multi-centre clinical trials.
Two types of clinical services must be clearly identified and interlinked through these managed clinical networks:

7.1 HIV units

HIV units providing outpatient care for the majority of patients with uncomplicated HIV infection. An HIV unit will as a minimum be staffed by:

- A consultant in HIV care.
- A specialist nurse.
- Specialist pharmacist.
- Specialist dietician.

This HIV outpatient service should be available locally (in tertiary sexual health centres) in most areas within each network. Patients should have a choice of which HIV unit to attend. These units will provide ongoing clinical care for adults with diagnosed HIV infection and should be under the direction of a consultant qualified to provide such care. Services for ongoing HIV care should include the following required provision:

- Case management for HIV as a long-term medical condition, with a focus on self-management and enabling adherence.
- Assessment and routine monitoring of HIV patients and initiation and monitoring of HAART in accordance with BHIVA and other relevant national and local guidelines.
  - Asymptomatic patients should be monitored for the development of symptoms together with CD4 counts and viral loads.
  - Antiretroviral therapy provided in accordance with BHIVA national guidelines and adequate support provided to ensure compliance with drug regimens.
- Access to specialist nursing within the local area.
- Specialist pharmacist support, either through local staff or via outreach from the HIV centre.
- Good links with mental health services with agreed referral pathways for psychology and psychiatric service.
- Appropriate laboratory services to support access to all relevant tests recommended in BHIVA guidelines for monitoring patients on and off HAART.
- Access to health advisor/counsellor as required.
- Access to peer support.
- 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.
- Facilities for partner notification.
- Health promotion services, provision of condoms and lubricants.
- GU/sexual health screening and services.
• Sexual health care must be integrated into the routine clinical practice of HIV units, including on-going risk assessment and screening for other blood borne viruses with appropriate immunisations offered.

• Access to contraception and pre-conception care.
• Cervical cytology for HIV positive women if indicated.
• Clearly defined arrangements for network access to all HIV centre services including 24-hour advice.

Non-clinical aspects of these services may be delivered outside clinical settings and in partnership with a range of NHS and non-NHS providers, but there must be effective overseeing and co-ordination of multi-agency work to deliver the various service components, including clearly defined arrangements for liaison with generic and voluntary services.

7.2 HIV centre

More specialised aspects of HIV should be provided through an HIV centre, which may be on a single site or may take the form of a ‘virtual HIV centre’ comprising an interlinked cluster of a small number of providers within a group. In the case of such a virtual HIV centre, the role of each individual provider should be clearly defined.

The medical staff of the HIV centre (whether virtual or single-site) should include a substantive body of consultant expertise covering a range of clinical aspects of HIV able to provide care directly and to advise and support colleagues at HIV units and other clinical services within the network area.
Other staff should include:

• One or more dedicated HIV specialist pharmacists.
• One or more dedicated specialist HIV dieticians.
• One or more consultant or equivalent senior clinical nurses.
• Access to specialist HIV virology service.

The HIV centre should function as an HIV unit in its own right and as a support to colleagues in HIV units elsewhere in the network. As such it should be able to work across organisational boundaries.

Each provider of acute medical HIV inpatient care must be staffed by enough consultants qualified to provide HIV inpatient care to enable a sustainable rota for 24-hour cover. Each such provider must be located at a hospital with a full range of general medical services including intensive care on-site. The HIV centre consultants must have direct access to inpatient beds. Day case/ambulatory facilities should also be available within the HIV centre.

• When planning HIV centres, consideration should be given to co-location with:
  • Hepatology.
  • Respiratory medicine for diagnosis and tuberculosis management, including negative pressure facilities.
• Oncology.
• Neurology and neurosurgery.

• In addition to the above services there must also be direct access to, and close liaison with, the following related services:
  • Endocrinology.
  • Renal medicine.
  • Haematology/haemato-oncology.
  • Mental health for patients with significant mental health needs – including clinical psychology and liaison psychiatry able to engage with community mental health services in patients’ place of residence.
  • Dermatology.
  • Otorhinolaryngology.
  • Gastroenterology, especially endoscopy.
  • Lipid, hypertension and cardiovascular medicine.
  • A full range of diagnostic imaging and pathology.
  • 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).
  • Palliative care medicine.

• Arrangements must be in place to enable referral access to quaternary and supra-regional services:
  • Liver and renal transplantation.
  • Therapeutic drug monitoring and its interpretation.
  • Specialist management of multi-drug resistant TB.
  • More specialised HIV virology services.
  • 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 centres itself.

There must be network-wide arrangements for 24-hour access to specialist HIV advice. These must be agreed with acute medical and accident and emergency departments within the area covered by the network, as well as to HIV units.

### 7.3 Other functions of the network

The regional clinical networks will support primary medical and dental services in ensuring that all those with HIV have access to good quality medical and dental care. In collaboration with sexual health networks they will:
- Support training and education and development to ensure that all GPs and dentists are aware of the signs, symptoms of and risk factors for undiagnosed HIV infection, are confident in their ability to provide pre and post test counselling and understand the care pathways for referral to specialist services.
- Ensure that all people with HIV have access to dental care and signpost individuals to named providers of dental services.
- Support the implementation and publicising of policies on arbitrary discrimination and confidentiality and dispel myths and misinformation that still persists about the insurance implications of HIV etc.
- The clinical network will contribute to the local sexual health networks so that services can be planned through multidisciplinary collaboration with participation from users and commissioners.
## 8. Service Components and Indicators

<table>
<thead>
<tr>
<th>Service Activity</th>
<th>Outcomes</th>
<th>Indicators/targets</th>
<th>Evidence</th>
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<tbody>
<tr>
<td><strong>1. Testing for HIV infection</strong>&lt;br&gt;Early diagnosis of HIV infection</td>
<td>Universal (opt out) testing in place in the following tertiary services - GUM and antenatal clinics&lt;br&gt;Increased testing in community settings and primary care&lt;br&gt;Testing for HIV infection in those presenting with TB, Hep B or C or lymphoma</td>
<td>Relevant staff appropriately trained and written information available for client group&lt;br&gt;Primary care supported by HIV networks and procedures in place for testing hard to reach groups&lt;br&gt;Local protocols in place</td>
<td>% of women attending antenatal services who are tested for HIV infection&lt;br&gt;Uptake of tests in GUM services&lt;br&gt;Number of tests performed in GUM clinics and other settings&lt;br&gt;Number of new HIV diagnoses where CD4 count is less than 200</td>
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<tr>
<td><strong>2. Laboratory Services</strong>&lt;br&gt;Timely diagnostic services available across Wales</td>
<td>All primary screening laboratories offer HIV antibody testing and p24 antigen test&lt;br&gt;Routine HIV testing available within 72 hours, antenatal test results within 5 days and urgent test results available in 24 hours&lt;br&gt;Test results available within the hour for exceptional clinical circumstances</td>
<td>All screening laboratories have policies and procedures in place to provide tests to the agreed timescales&lt;br&gt;Protocols in place and agreed with local network for test results to be available within the hour for exceptional clinical circumstances</td>
<td>Feedback from regional HIV network&lt;br&gt;Feedback from regional HIV network&lt;br&gt;Protocols in place</td>
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<td><strong>3. Assessment after diagnosis</strong></td>
<td>Newly diagnosed patients have access to care within 2 weeks in specialist HIV Unit; Consultant led and supported by, specialist nurse, pharmacist and dietician</td>
<td>All newly diagnosed patients assessed within 2 weeks</td>
<td>Patient satisfaction survey undertaken annually by clinics and collected by regional HIV network</td>
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<td></td>
<td>Newly diagnosed HIV positive patients referred for supportive care</td>
<td>Protocols in place for patient referral for supportive care; this must be with the consent of the patient</td>
<td>Annual Patient satisfaction survey</td>
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<td>Written information available for patients and carers</td>
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<td>Written information available and agreed by network</td>
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<td><strong>4. Patient education and shared decision making</strong></td>
<td>Culturally appropriate education/information and peer support available for all</td>
<td>Culturally appropriate education/information shared across all providers and protocols for referral for peer support available</td>
<td>Written information available and shared between local providers of care</td>
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<tr>
<td>Developing the expert patient</td>
<td>Individual care plans agreed in partnership with the patient, the voluntary sector and social services (if required)</td>
<td>All patients have a care plan agreed in partnership with the voluntary sector and social services (if required)</td>
<td>Evidence of regular meetings with all partners in care provision</td>
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<td>HIV positive patients encouraged to become expert patients</td>
<td>All staff are supported in educating patients on the benefits of the expert patient and referral processes understood</td>
<td>Individual care plan accessible by HIV network</td>
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<td>% of newly diagnosed HIV positive patients who have/are attending Expert Patient Groups collected annually by HIV network</td>
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<td><strong>5. Clinical Management</strong></td>
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<td><strong>5.1 Adult care</strong></td>
<td>Compliance with BHIVA guidance for:</td>
<td>HIV units and centres implement BHIVA guidance and local policies and care plans reflect this</td>
<td>Annual audit by HIV network</td>
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<tr>
<td></td>
<td>• First line HAART therapy</td>
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<td>• Patient monitoring</td>
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<td>• Management of drug resistance</td>
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<td>Patients with uncomplicated asymptomatic HIV infection, on or of HAART are monitored in HIV unit outpatients</td>
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<td>Networks, have as a standing agenda item the review of all patients who fail to achieve or maintain virological suppression on HAART</td>
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<td>Protocols for appropriate choice of therapy available to all HIV units in the network</td>
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<td>HIV units and HIV centers will agree referral processes for a range of services detailed within the service specification</td>
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<td>HIV network will report annually on co-morbidity for the population accessing care</td>
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<td><strong>Service Activity</strong></td>
<td><strong>Outcomes</strong></td>
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<tr>
<td>5.2 Pregnancy</td>
<td>An individual perinatal care plan will available for all HIV positive mothers</td>
<td>All units have a named consultant obstetric and paediatric lead and policies and procedures in place to ensure care plan agreed and implemented</td>
<td>Report on local management of HIV positive mothers prepared annually and submitted to the network</td>
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<tr>
<td>5.3 Paediatric care</td>
<td>HIV positive children managed in service networks supported by specialist nurse, pharmacist and dietician</td>
<td>HIV centre and regional paediatric HIV centre are involved in all care plans - Managed transition of adolescent care to adult services</td>
<td>Care plans audited by the HIV centre annually</td>
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</tbody>
</table>
| 6. Supportive care  | All local services for are well integrated and networking | Regular meetings with service providers within the LHB and network area | Annual report identifying:  
- Meetings attended  
- Network approach taken  
- Joint working  
- Information dissemination and signposting  
- Up to date resource directory  
- Lessons learnt that can be used for service improvement  
- Up to date and agreed care pathway |
|                      | HIV positive people know how and where to access HIV support services that are consistent with their diverse needs | Accurate knowledge of services available within LBH area is maintained and evidenced. This information to be provided to LHB service providers and people living with HIV to enhance networking and service access  
A web based resource directory on services is available | Annual report identifying:  
- Group programmes run and numbers participating (by ethnicity, gender, age and sexuality) |
<p>|                      | Proportion of positive population accessing range of services is improved |  |  |</p>
<table>
<thead>
<tr>
<th>Service Activity</th>
<th>Outcomes</th>
<th>Indicators/targets</th>
<th>Evidence</th>
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<tbody>
<tr>
<td>Carers linked to carers support service</td>
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<td>• Numbers of people receiving individual support (by ethnicity, gender, age and sexuality)</td>
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<td>• Number of individual peer support sessions</td>
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<td>• Number of individual counselling sessions</td>
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<td></td>
<td>• Numbers of people using services engaged in education, training or employment (by ethnicity, gender, age and sexuality)</td>
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<td>• Service user plan, and progress against plan</td>
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<td>• Specific details of partnership working with social care and health services, and support offered</td>
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<td>• Feedback from service users and their experiences of services</td>
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<td></td>
<td>• Analysis of any new or emerging trends with this client group</td>
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<tr>
<td>Increased access to testing for hard to reach groups including Black Africans</td>
<td>Improve access to and/or provide HIV testing to hard to reach groups</td>
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<td>Number of individuals accessing HIV testing outside clinical settings</td>
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<td>A process is undertaken to develop and</td>
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<td>Service Activity</td>
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<tr>
<td>Hard to reach groups</td>
<td>Short term evidence based individual and group support available for people living with HIV and those who care for them</td>
<td>regularly review clear and up to date care pathways for those currently living with HIV and those newly diagnosed, engaging all key stakeholders</td>
<td>Current case load and outcome of regular review process to be shared with LHB and service providers at regular meetings</td>
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<td>Promote self management by providing those living with HIV the necessary supports to positively manage their own health and well being</td>
<td>Providers share ethos and principles of support in line with the current thinking on the management of Long Term Conditions, and the social model of disability.</td>
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<td>Positive people are effectively self managing their health and secondary infection or illness rates are low</td>
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<td>Annual review of case load</td>
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<td>Support targeted at hard to reach groups Black and other Ethnic minority groups</td>
<td>Specific services for Black African and other hard to reach groups established 60% of identified positive people in this cohort are in contact with the service and have been offered group support or individual peer support or counselling.</td>
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<td>Annual report identifying:</td>
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<td>• Group programmes run and numbers participating (by age, gender and ethnicity)</td>
<td>• Group programmes run and numbers participating (by age, gender and ethnicity)</td>
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<td>• Number of individual peer support sessions</td>
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<td>• Specific details of partnership working with, social care and health services including contribution to care plans</td>
<td>• Specific details of partnership working with, social care and health services including contribution to care plans</td>
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<td>• Feedback from client about their experiences of services</td>
<td>• Feedback from client about their experiences of services</td>
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<td>Service Activity</td>
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<tr>
<td>Young people (for the purpose of this specification this includes all HIV positive individuals up to 25 years)</td>
<td>Young people affected by HIV have access to effective, youth appropriate, evidence based support services</td>
<td>Specific service for Young People with HIV is established and accessible to young people. 60% of identified positive young people are in contact with the service and have been offered group support or individual peer support or counselling. Positive young people and those affected by HIV are involved in the service design and delivery. Parents of young people living with or affected by HIV have been offered support. Service is well networked with local CAMHS, LA Children’s Services; Community Paediatrics Service; School Nursing Service; primary care and other relevant health education and social care Services and local HIV networks. Parents of young people living with or affected by HIV have been offered support</td>
<td>• Analysis of any new or emerging trends with this client group. Annual report identifying: • Group programmes run and numbers participating (by age, gender and ethnicity) • Numbers of young people receiving individual support (by age, gender and ethnicity) • Number of individual peer support sessions • Number of individual counselling sessions • Numbers of young people using services engaged in education, training or employment • Youth participation plan, and progress against plan • Specific details of partnership working with education, social care and health services • Feedback from young people and parents about their experiences of services • Analysis of any new or emerging trends with this client group.</td>
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<td>Access to education and employment opportunities is increased</td>
<td>Access to support for parents of young people living with or affected</td>
<td>Transition protocol agreed by all</td>
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<td>Access to support for parents of young people living with or affected by HIV</td>
<td>Support services networked/integrated with social and clinical care</td>
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<td>Service Activity</td>
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<td>Access to support for transition to adult services</td>
<td>stakeholders to support transition to adult services</td>
<td>LHBs have assessed the quantity and quality of palliative care services in different settings</td>
<td>Report on needs assessment shared with the network</td>
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<td>7. Palliative care</td>
<td>Each person, at the end of life receives coordinated care, in accordance with an agreed care plan</td>
<td>Protocols and procedures for accessing palliative care are in place – developed in partnership with statutory and non statutory providers of care</td>
<td>Protocols and procedures reviewed annually</td>
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<td>Carers and families are supported</td>
<td>Individual care plan are developed with patients as the end of life approaches</td>
<td>Feedback from carers about the quality of the service</td>
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<td>Information, culturally appropriate, is available for patients and families</td>
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<td>The needs of carers and the support they may require will be included in care plans</td>
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<td><strong>8. Social Care</strong></td>
<td>Social care is integrated and networked with NHS services and voluntary sector</td>
<td>Regular meetings with service providers within the LHB and network area</td>
<td>Annual report identifying</td>
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<td>HIV positive people know how to access support from social services and understand the range of services provided</td>
<td>Accurate knowledge of services available within LBH area is maintained and evidenced</td>
<td>• Meetings attended</td>
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<td>Patients are offered choice and control and their independence is promoted; carers are recognised and fully informed; have their needs recognised; and are supported in their caring role; and,</td>
<td>Information will be made publically available about the services which may be arranged by social services; what it is possible and not possible to supply; and the way in which help can be requested</td>
<td>• Network approach taken</td>
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<td>Service consider all a person’s needs whether they be housing, health, employment or social security and respond to agreed timeframe.</td>
<td>A process is undertaken to develop and regularly review clear and up to date care plans for all persons receiving support – both those currently living with HIV and those newly diagnosed Carers needs will be considered in the development of the care plans</td>
<td>• Joint working with defined contribution to individual care plans</td>
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<td>Social services will respond within 2 days of referral and deliver agreed support within 28 days -considering all the needs of the clients</td>
<td>• Information dissemination and signposting</td>
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<td>• Up to date resource directory</td>
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<td></td>
<td>Information on service provision shared with all local providers of care both statutory and non statutory</td>
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<td>Annual satisfaction survey of patients and carers</td>
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<td>Annual report detailing:</td>
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<td>• Number of referrals (by age, gender and ethnicity)</td>
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<td>• Number of assessments made</td>
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<td>• Type of support requested and the support delivered with timeframes</td>
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<td>• The review process</td>
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Appendix 1

Membership and terms of reference of Task and Finish Group

In recognition that HIV and AIDS now need to be seen as chronic conditions rather than exclusively terminal conditions, the Minister for Health and Social Care requested that a small HIV/AIDS task and finish group be established to develop the following, which needs to consider the various services needed, both health and social, and who might be best placed to provide these various services, including the voluntary sector;

1. A care pathway that covers detection, diagnosis, treatment and palliative and supportive care, including social care, for HIV and AIDS
2. A revised service specification to inform Local Health Board and Social Services planning and funding in order to deliver the care pathway.

Membership of the task and finish group and project group

Chair
Richard Evans
Consultant in Infectious Diseases, Cardiff and Vale NHS Trust,

Members

Andrew Freedman
Consultant in Infectious Diseases, Cardiff and Vale NHS Trust,

Kathir Yoganathan
Consultant in GUM medicine, Abertawe Bro Morgannwg University NHS Trust

Jennifer Evans
Paediatric HIV consultant, Cardiff and Vale NHS Trust

Fiona Clark
HIV specialist pharmacist, Cardiff and Vale NHS Trust

Rosemary Johnson
All Wales Antenatal Screening coordinator

Jackie Redding
Director of Clinical Care and Service Development, Terrence Higgins Trust

Sarah Staveley
HIV Nurse Specialist, North Wales NHS Trust

Siobhan Miles
HIV Nurse Specialist, Abertawe Bro Morgannwg University NHS Trust

Liz McCruden
Virologist, NPHS
Members of the task and finish group have been selected because they can provide a range of experience and expertise in HIV service provision. Specifically they will:

1. Shape the strategic direction of the work.
2. Ensure that local considerations relevant to the care pathway are taken into consideration.
3. Ensure that the care pathway and specification is consistent with national policy on sexual health, sexual health services and the management of chronic conditions, and are evidenced based.
4. Monitor, review and approve the care pathway and service specification as they develop to the agreed timescale.
Appendix 2

Source Documents


Designed to Improve Health and the Management of Chronic Conditions in Wales, Service Improvement Plan 2008-2011.

British association for Sexual health and HIV (BASHH), British HIV Association (BHIVA) and the British Infection Society (BIS) UK National Guidelines for HIV Testing 2008. www.dh.org.uk


BHIVA guidelines: Management of sexual and reproductive health (SRH) of people with HIV infection (2008) www.bhiva.org


CHIVA guidelines: Paediatric Protocols, Treatment, Trials and Guidelines www.chiva.org.uk

PENTA guidelines on the use of antiretroviral therapy in paediatric HIV infection Draft 2008 www.pentatrials.org

HIV-AIDs and Social Care, discussion paper. K Tolley, A Maynard, D Robinson, Universities of York and Hull. www.york.ac.uk

Policy Guidance on integrating HIV health and social care services. www.tht.org.uk

A Guide to Services for People Affected by HIV. City and County of Swansea www.swansea.gov.uk

Service Specification HIV support services - Hammersmith and Fulham Primary Care Trust

Appendix 3

Glossary of Abbreviations

ART Antiretroviral therapy
ASW Antenatal Screening Wales
BASHH British Association for Sexual Health and HIV
BHIVA British HIV Association
CAMHS Children and adolescent Mental Health Services
CD4 count Marker of likely disease progression
CDC US Centre for Disease Control and Prevention
CE-marked European quality mark
CPA Clinical Pathology Accreditation
DBS Dried Blood Spot
ELISA Enzyme-Linked ImmunoSorbent Assay
GMC General Medical Council
GP General Practitioner
GPC Wales General Practitioner Committee
GUM Genito Urinary Medicine
HAART Highly active antiretroviral therapy
HBV Hepatitis B Virus
HCV Hepatitis C Virus
HIV Human immunodeficiency virus
LA Local Authority
LHB Local Health Board
LSCS Lower segment Caesarean section
MHRA Medicines and Healthcare products Regulatory Agency
MSM Men who have sex with Men
MTCT Mother to Child Transmission
NNRTIs Non-nucleoside reverse transcriptase inhibitors
NPHS National Public Health Service
OPIM Other potentially infectious material
PCR test Polymerase chain reaction test
PEP Post Exposure Prophylaxis
PEPSE Post Exposure Prophylaxis following potential sexual exposure
POCT Point of Care Testing
RNA Ribonucleic acid
ROM Rupture of membranes
STI Sexually Transmitted Infection
TB Tuberculosis
VL Viral Load
WAG Welsh Assembly Government