# Standards for HIV care: draft for consultation

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# 1. Background and principles

## 1.1. Scope of standards

In preparing this report, BHIVA has sought to produce a limited set of focussed, auditable standards which address key aspects of the organisation of NHS clinical care for adults with HIV infection.

As such, this report is not intended as a comprehensive guide to good practice in HIV medicine. It should be read alongside BHIVA's clinical guidelines[1] and other relevant standards, recommendations and guidelines, including earlier standards developed by the Medical Foundation for AIDS and Sexual Health which give a broader perspective on good practice[2]. The clinical guidelines make recommendations about what treatments/interventions patients should receive, whereas this document focuses on where and by whom care should be provided.

Although this document mentions PCTs and other NHS organisations that exist only in England and Wales, BHIVA believes that the principles and approach it sets out are broadly applicable across the UK as a whole.

There have been dramatic changes since HIV emerged in the 1980s, which necessitate corresponding changes in service provision. These standards aim to define a new care paradigm in line with the following principles:

## 1.2. Entitlement to care

BHIVA believes that every person with HIV is entitled to a uniformly high standard of medical care. These standards are therefore applicable to the care of all adults living with HIV in the UK.

## 1.3. The chronic disease paradigm

HIV has become a complex, chronic medical condition, and the model of care should be based on that of other such conditions. However, HIV does retain some exceptional features, which are reflected in the standards recommended below:

- Even the routine elements of HIV care are relatively complex and rapidly developing, involving specialised tests and combinations of drugs with significant potential for toxicity and interactions.
- The prevalence of HIV is increasing through new diagnoses and improved survival, but remains patchy and low in some areas. In 2004, 40265 HIV patients of all ages were seen for care in England, Wales and Northern Ireland, 22642 within the London SHAs, and 1911 HIV infected persons were receiving specialist care in Scotland (see Annex).
- HIV continues predominantly to affect minority groups – gay men, Black-Africans, refugees and asylum seekers, and injecting drug users – who are vulnerable to stigma, and in some cases severely disadvantaged. It is itself a stigmatised condition. Particular attention is therefore required to issues of trust, confidentiality and reducing inequalities.
- HIV is a sexually transmissible infection. It is highly associated with mutually complicating infections including TB and hepatitis B & C.

[1] Regularly updated, available from http://www.bhiva.org.

[2] Medical Foundation for AIDS and Sexual Health, 2002. Recommended standards for NHS HIV services.

- HIV disease can affect any or all bodily systems and present via a wide variety of conditions, for example malignancies, opportunistic infections or renal failure. No single clinician can be expected to manage all possible manifestations of HIV disease to a high standard.
- HIV treatment including ART is undeniably costly, but cost-effective in view of its dramatic impact on survival and quality of life[3] [4].

### 1.4. Quality of care

The recommendations set out in this document are designed to reflect the *required* level of care which should be achieved throughout the NHS, not a gold standard for quality. Some of the recommendations are supplemented with illustrative examples of good practice. The latter are not requirements, and may not represent the only satisfactory model of service delivery.

### 1.5. Efficiency

Efficient use of public resources should be sought through streamlining and modernising service provision wherever this can be achieved without detriment to patient care.

### 1.6. Individual and public health

Planning of HIV treatment and care services must have regard to public health protection through prevention of HIV, other STIs and related infections including TB, in addition to the best interests of the individual patient.

# 2. Commissioning, service networks and levels of care

### 2.1. Recommendations

#### *2.1.1. Commissioning and clinical networks*

NHS commissioners must collaborate in planning HIV treatment services across geographical boundaries and multiple providers to make best use of resources and expertise. For England, this means that HIV treatment services should remain within the Specialist Services National Definitions Set and Strategic Health Authorities should take an active lead.

Although this document is primarily concerned with clinical services for adults with diagnosed HIV infection, commissioning plans must encompass the full range of services necessary for HIV care, management and control, including:

- Voluntary and community development organisations for communities particularly affected by HIV.
- Social care and welfare advice 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.

[3] Trueman P, Youle M, Sabin CA, Miners AH, Beck EJ. HIV Clin Trials. 2000 1:27-35.

[4] Beck EJ, Mandalia S, Gaudreault M, Brewer C, Zowall H, Gilmore N, Klein MB, Lalonde R, Piche A, Hankins CA. AIDS. 2004 18:2411-8.

- Sexual health promotion and HIV prevention services, including access to condoms, sterile injecting equipment and post-exposure prophylaxis for sexual and occupational exposures.
- Drug and alcohol services.
- Services for prisoners, commercial sex workers and other vulnerable groups.
- Expansion of access to HIV testing and diagnosis.

Clinical care for diagnosed HIV infection in adult patients should 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.

Two types of clinical services must be clearly identified:

- Tier 1 HIV outpatient care for the majority of patients with uncomplicated HIV infection. This should be available locally in most areas within each network. Patients should have a choice of whether to attend their most local provider or an alternative service.
- Tier 2 HIV services for patients with more specialised needs, which should be provided through a designated[5] single-site centre or cluster centre in each network. These services include complex outpatient care, inpatient care and referral/advice services[6].

The following activities should be managed at the network level:

- Development and implementation of clinical and communication protocols and referral pathways (see also *The patient journey* below)
- 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
- Public and patient involvement
- Allocation of resources in a fair and transparent manner
- Planning of new service developments
- Access for eligible patients to multi-centre clinical trials, coordinated via the tier 2 centre.

### *2.1.2. Tier 1 outpatient HIV provision*

Ongoing clinical care for adults with diagnosed HIV infection should be under the direction of a consultant qualified to provide tier 1 HIV 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

[5] Subject to the implementation of the review of specialised commissioning, providers of tier 2 HIV services should be formally designated as specialised service providers by the relevant Specialist Commissioning Group. See recommendation 17 of *Review of Commissioning Arrangements for Specialised Services: May 2006. An independent report requested by the Department of Health.*

[6] See *The patient journey*, below, for categorisation of different aspects of clinical care as tier 1 or tier 2 services.

- Assessment and routine monitoring of HIV patients and initiation and monitoring of ART in accordance with BHIVA guidelines
- Appropriate laboratory services to support access to all relevant tests recommended in BHIVA guidelines[7] for monitoring patients on and off ART
- Access to health advisor/counsellor
- Facilities for partner notification
- GU/sexual health screening
- Treatment support including patient education
- Clearly defined arrangements for network access to tier 2 services including 24/7 out of hours advice
- Health promotion services
- Access to specialist nursing within the local area
- Effective oversight and co-ordination of multi-agency work to deliver the various service components, including clearly defined arrangements for liaison with generic and voluntary services.

### *2.1.3. Designated providers of tier 2 HIV services*

More specialised aspects of HIV should be provided through a designated tier 2 centre, which may be on a single site or may take the form of a "virtual centre" comprising an interlinked cluster of a small number (eg 2-4) of providers within a network. In the case of such a virtual centre, the role of each individual provider should be clearly defined, in particular whether it includes:

- Acute medical HIV inpatient care
- Other specialised tier 2 services excluding acute medical HIV inpatient care only.

The medical staff of the designated tier 2 HIV centre (whether virtual or single-site) should include a substantive body of consultant expertise covering a range of clinical aspects of HIV. Other staff should include one or more dedicated HIV specialist pharmacists and one or more consultant or equivalent senior clinical nurses able to work across organisational boundaries and support colleagues elsewhere in the network.

Each designated tier 2 provider of acute medical HIV inpatient care must be staffed by enough consultants qualified in 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 tier 2 HIV centre.

When planning tier 2 HIV centres, consideration should be given to co-location with:

- Hepatology
- Tuberculosis management, including negative pressure facilities
- Oncology
- Neurology and neurosurgery.

In addition there must be direct access to and close liaison with the following related services:

[7] Guidelines are subject to change as evidence evolves, but currently this includes HIV diagnostics, viral load and resistance testing, and CD4+ lymphocyte counts. If abacavir-based ART is considered, genetic testing for the HLA B57*01 allele is also necessary to minimise the risk of hypersensitivity reactions.

- Endocrinology
- Renal medicine
- Haematology/haemato-oncology
- Mental health for patients with significant mental health needs – including 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 services.
- Ophthalmology
- Dental/oral medicine
- Dietetics, physiotherapy, occupational therapy and clinical psychology
- Fertility and obstetrics – including liaison midwifery
- Access to bone marrow transplantation (for lymphoma patients).

Arrangements must be in place to enable referral access to quarternary and supra-regional services:

- New Fill
- Liver and renal transplantation
- Therapeutic drug monitoring and its interpretation
- HIV virology including interpretation of complex resistance patterns
- 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 tier 2 centre itself.

There must be network-wide arrangements for 24 hour on call/referral advice, provided via the tier 2 inpatient HIV care service. These must be published to acute medicine and accident and emergency departments within the area covered by the network, as well as to tier 1 HIV service providers.

#### *2.1.4. General practice and primary care*

GPs should coordinate care for non-HIV related conditions affecting people with HIV as for other patients, in accordance with relevant national service frameworks, standards and guidelines, and wherever possible in liaison with HIV services.

HIV services should strongly advise patients to register with a GP and to inform their GP of their HIV status and medication.

## 2.2. Background and rationale

### *2.2.1. Commissioning and clinical networks*

Because of relatively small numbers and a high level of complexity, efficient planning of health services for people with HIV requires a strategic approach across substantially larger areas than individual PCTs or health boards. This is best achieved through managed clinical networks with defined roles for each provider, with the following activities managed at the network level:

- Development and agreement of referral triggers and pathways to deliver care safely and efficiently and to ensure patients have equal access to services according to their clinical needs, irrespective of their usual provider within the network (see recommendations below relating to the patient journey).
- Mutual professional support and ongoing clinical education to enable all clinicians to maintain up to date skills and knowledge appropriate to their clinical roles.
- Governance including quality assurance and audit.
- Development of IT and communication pathways to support patient care, including arrangements for 24 hour advice on the management of complex cases.

BHIVA anticipates that a later stage of this project will include mapping service provision (in collaboration with commissioners) to identify network boundaries and sites for tier 2 services.

Each network should have a consultant clinical network lead (with protected time in his/her job plan) whose roles will include facilitating protocol development and decision-making among the centres/units participating in the network. A funded non-clinical manager post is also needed to coordinate network activities.

Outside the main scope of this document, there should also be a broader service network encompassing community and social care providers working in liaison with the clinical network. This requires health commissioners to develop strong and effective strategic partnerships with local government and other partners serving their local populations, in addition to working across geographical boundaries to commission clinical services.

### *2.2.2. Tier 1 outpatient HIV provision*

As for other chronic diseases, case management can play a key role in keeping people with HIV well and avoiding complications or symptomatic disease and hence the need for more specialised services or emergency hospital admission. A proactive approach is needed which places the person with HIV at the centre and integrates routine monitoring, self management, primary and social care. However, case management for HIV differs from other conditions:

- Patients are younger and overwhelmingly from specific minority groups, ie gay men and black-Africans. While some experience day to day symptoms which are disabling to a greater or lesser extent, many do not.
- Monitoring relies on interpretation of specific blood tests which are not used in other areas of medicine.
- HIV therapy is exceptionally complex, and rapidly developing. The knowledge-base patients need to adhere well to their therapy is highly specific to HIV.
- Case management is concerned with prevention of onward transmission of HIV and other STIs as well as maintaining personal health.

Because of these differences and low prevalence, it is more efficient for case management to be overseen and coordinated by the HIV outpatient service, where possible in partnership with

voluntary/patient-led organisations[8], than by general practice or other generic provision[9]. This does not necessarily mean delivering services in conventional hospital outpatient clinics[10]. The key issues are the skill and knowledge-set and facilities, rather than location. Some outpatient providers are modernising to provide routine monitoring by nurse specialists in a variety of settings; this is good practice which appears to be well-liked by patients, may reduce pressure on clinic facilities, and may be cost-saving.

There are concerns about current routine care, since around one in five patients with advanced immunosuppression (CD4 count under 200 cells/µl) are not on ART[11]. Such patients are at high short term risk of opportunistic illness, which ART could prevent, and also likely to be highly viraemic and infectious to sexual partners. Uptake of ART among such patients varies greatly by region as well as by age and clinical stage, though not by sex, ethnicity or HIV exposure category, suggesting that provider factors may play a part. Recently diagnosed patients account for a relatively small proportion of those with low CD4 counts not on treatment. BHIVA believes that better network support is needed to ensure clinicians do not practise in isolation; all outpatient providers need explicit network links with larger centres. One approach is to have a regular (weekly) day on which tier 1 consultants attend a tier 2 centre to take part in a ward round, network meeting and CME or clinical governance event. It is also good practice for clinicians who provide tier 2 services to undertake outreach and travel to tier 1 providers, for example to provide a regular monthly joint clinic.

The problem of isolation may be particularly severe for HIV specialist nurses involved in tier 1 care provision, since nurses are traditionally employed by a single trust without a recognised need for external professional contact[12]. Within each network there should therefore be at least one senior (eg nurse consultant) HIV specialist nurse whose contract explicitly provides for cross-boundary working to liaise with and support colleagues in other trusts. Service modernisation towards more care being delivered through nurse-led clinics makes this increasingly important.

Treatment support is essential in enabling patients to cope with their condition and its therapy, including adherence to ART. There is no one model for provision of treatment support, which can involve specialist nurses, pharmacists and community treatment advocates. However specialist HIV pharmacists based at tier 2 centres have a distinct role in training tier 1 pharmacy staff so as

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[8] While there is much scope for mutual learning, the general consensus is that HIV patient education cannot be fully addressed via generic expert patient programmes, but requires a substantial HIV-specific component. HIV voluntary/patient organisations have a key role in this.

[9] "HIV/AIDS has become … "a chronic, manageable disease," perhaps not unlike diabetes, hypertension, or hyperlipidemia. Unlike these conditions, AIDS is a contagious, infectious disease, that if left untreated, almost invariably leads to death within eight to 10 years. It is a disease whose control depends on potent antiviral medications and whose natural history will not be affected significantly by dietary or lifestyle changes.

"… Currently, 20 drugs are available to treat HIV. Although guidelines for their use exist, decisions about treatment are complex. These include the decision to start antiretroviral therapy as well as the selection of a specific regimen. What follows is long-term monitoring for efficacy, compliance, adverse events, and resistance. In many cases, based on toxicity or new clinical trial data, a patient's antiretroviral regimen must be changed one or more times. *These are issues most family physicians will not have the training, time, clinical experience, or desire to cope with.*" [emphasis added] Kirchner J. Am Family Physician 73(2): 215-7, 2006.

[10] "Currently there are nearly 45 million outpatient appointments every year in England. Estimates vary by specialty, but for some specialties up to half of these could eventually be provided in a community setting." Department of Health. *Our health, our care, our say: a new direction for community services.* 2006.

[11] Bryant V, Chadborn T, Patel B, Delpech V. 12th Annual Conference of the British HIV Association, Brighton UK, 29 March-1 April 2006. Abstract O1. *HIV Medicine* 2006 **7 Suppl. 1:**1.

[12] *"When you look at outside London, the periphery of London, if you are talking about specialist nurses you talk about specialist nurses working in isolation … how would you then make sure that that the level of care is … equitable, that is on the same standard?"* Nathaniel Ault, at 24 July workshop.

to ensure correct prescribing and dispensing, as well as providing treatment support to patients. Specialist pharmacist input is independently associated with improved HIV viral load response[13] which in turn is associated with less risk of symptomatic disease. An example of good practice would be for tier 2 specialist pharmacists to provide sessional outreach to outpatient services..

Laboratory services are important in the routine care of HIV patients and should be of high quality, assured by participation in the Clinical Pathology Accreditation (UK) Ltd programme[14].

### *2.2.3. Tier 2 designated HIV centres*

Tier 1 outpatient provision represents the mainstay of HIV care and most patients can be safely managed through these services[15], in some cases with occasional advice from more specialist clinicians. However, at any time a minority will have complex needs which can only be safely managed at a larger centre with a sufficient concentration of HIV specialist expertise. The most common such complex needs relate to:

- Opportunistic infections and TB, in some cases leading to respiratory failure
- Liver disease associated with hepatitis B or C co-infection[16] and/or alcohol
- HIV-related tumours
- Non-standard medication requirements because of HIV drug resistance, interactions, toxicity or other similar issues.

Within each network there must be a core team of tier 2 HIV specialists large and diverse enough to cover these main areas directly. In addition, as HIV may affect any body system this core team will require input from a very wide range of other clinicians who combine an active interest in HIV with their own main specialty. The management of more complex HIV-related needs should thus be concentrated within a small number of providers both to achieve critical mass within the HIV team itself and to give clinicians in related specialties sufficient HIV exposure to maintain their interest.

In addition, for inpatient care, because patients may be extremely unwell a core requirement is for reliable 24 hour cover by specialists who are experienced in HIV and ideally have an acute general medicine background, together with a strong nursing team. As a very rough estimate, at any time there may be fewer than one patient requiring inpatient care per 100 adults with diagnosed HIV infection; this suggests that the minimum desirable caseload for a network may be around 750-1000 adults with diagnosed HIV infection to enable a viable dedicated HIV inpatient unit. The optimum size may be substantially larger. Where geographical considerations make such a caseload unfeasible, specific local arrangements are needed to meet inpatient care standards.

Specialist laboratory-based services including virology and therapeutic drug monitoring are important in optimising ART for patients with complex treatment problems such as multiple drug resistance, so preventing morbidity and maximising the long term effectiveness of costly third and subsequent-line regimens. Clinicians must be able to engage directly with experts in these areas to discuss and interpret problems jointly in the light of the individual patient's clinical history. Ongoing investment is needed for the development of new assays to meet future needs.

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[13] Castillo E, Palepu A, Beardsell A, Akagi L, Yip B, Montaner JS, Hogg RS. AIDS Care. 2004 May;16(4):446-57.

[14] See http://www.cpa-uk.co.uk

[15] For example, about 60% of HIV patients on ART are receiving first or second-line regimens. Sabin C, UK Collaborative HIV Cohort Study.

[16] See also British Society of Gastroenterology. *Care of Patients with Gastrointestinal Disorders in the United Kingdom: A Strategy for the Future.* 2006.

HIV-related diseases present in diverse and often atypical ways, requiring specialist pathology expertise for correct diagnosis. Autopsies are an important source of learning about disease presentation and often reveal conditions not recognised before death by the treating clinicians, while the accuracy of tissue diagnostics should be monitored via regular (eg 6-12 monthly) clinico-pathological reviews. This requires referral access to an interested specialist pathologist if one is not available within the tier 2 centre.

Most designated providers of tier 2 HIV services will also provide tier 1 care. In terms of planning and monitoring service provision, it is important to distinguish patients receiving tier 1 care from a provider that also offers tier 2 services from patients with a clinical need for specialist tier 2 services.

**Virtual or cluster tier 2 centre examples**

Greater Manchester area: there is a managed clinical network comprising several tier 1 providers, two hospitals which provide some tier 2 services including inpatient care to their own patients but which do not accept incoming referrals, and one large main centre which provides comprehensive tier 2 services including referrals. The latter three providers can be viewed as a virtual or cluster tier 2 centre arrangement. Current staffing may not fully meet the recommendations in this report for provision of inpatient care, but the existence of a well-managed and structured network gives scope for development to address this.

North-East London: There are a number of tier 1 providers and two hospitals provide inpatient care, one of which receives incoming referrals and provides a full range of tier 2 services for all provider units. However appropriate local expertise in certain specialisms, such as pregnant women, has developed at tier 1 providers based on local need. Service planning may therefore proceed by developing some or all of this group of providers as a virtual/cluster tier 2 centre within which each has an appropriately defined role.

#### *2.2.4. General practice*

Over the course of HIV disease, many people will experience concurrent health problems including other chronic conditions such as asthma, hypertension etc. The standard of care for HIV patients with such diseases should be no lower than for other patients. HIV specialist clinicians generally lack the expertise to manage such all such conditions safely in line with relevant standards; GPs are better qualified to do so.

GPs need ready access to HIV specialist advice when treating patients who are on ART and/or have advanced HIV disease, even for routine problems, because of the scope for serious interactions between some ART drugs and a wide range of other medications and because of the risk of underestimating the seriousness of certain conditions in the immunocompromised patient. Hence patients need to understand that care can only be safely delivered if the GP is aware of the HIV diagnosis and able to liaise with the HIV specialist.

There is no universal model for effective primary care for patients with HIV. Some HIV services have established links with GPs interested in HIV and encourage their patients to register with these; where geographically feasible, this is good practice in facilitating liaison. Some HIV services offer sessional work by GPs within the HIV clinic setting. All should be pro-active in advising patients to register with a GP and in liaising with the GP of the patient's choice.

There is also scope for increased primary care involvement in management of HIV itself, on a shared-care basis. For example patients who require frequent monitoring for conditions such as anaemia may find it much more convenient to attend a general practice than a hospital provider, while specialist nurse-led tier 1 outpatient clinics could potentially be held in primary care premises. A minority of interested GPs with substantial numbers of HIV patients may provide clinics themselves in conjunction with a qualified tier 1 HIV consultant, in which case they should be fully

integrated alongside other providers within the HIV clinical network. Commissioning arrangements should be developed to support such flexible ways of working.

# 3. Clinical training, experience and commitment

## 3.1. Recommendations

### *3.1.1. Network roles*

All future consultant appointments[17] for posts providing HIV care should be made in the context of a defined HIV clinical network. The job description must specify the role the post occupies within the network, including whether it covers provision of:

- Tier 1 HIV care only
- Tier 2 services other than on-call advice and care for HIV inpatients
- Tier 2 services including on-call advice and care for HIV inpatients.

Job plans for all consultants providing HIV care must include defined time for HIV network activities.

Each network should have a designated consultant clinical lead. This role may rotate within the network but the current holder's job plan must allow sufficient time for network leadership.

### *3.1.2. Medical training and qualifications*

Future appointees to consultant posts providing HIV care must have obtained the Diploma in HIV Medicine. They must:

- EITHER have completed foundation training in general internal medicine (or equivalent for overseas qualified candidates) and hold and maintain specialist certification in a relevant medical specialty
- OR have completed foundation training in obstetrics and gynaecology (or equivalent for overseas qualified candidates) and hold and maintain specialist certification in GUM[18].

In the case of tier 2 posts which include provision of on-call advice and care for HIV inpatients, future appointees must have completed foundation training in general internal medicine (or equivalent for overseas qualified candidates) and must hold and maintain specialist certification in a relevant medical specialty.

### *3.1.3. Continuing professional development*

All consultants providing HIV care must participate in CME directly related to HIV on at least an annual basis. For those involved in provision of tier 2 services, this must include activities at the national and/or international level.

In addition, those consultants who provide 24 hour on-call advice and care for HIV inpatients must participate in CME related to general internal medicine on at least an annual basis.

[17] New posts and replacement appointments for existing posts.

[18] See http://www.jchmt.org.uk/gum/index.asp and http://www.pmetb.org.uk/media/pdf/3/t/PMETB_Genitourinary_Medicine_SSG.pdf

Job plans for consultants who provide tier 2 services must include at least 3 PAs/week in total for HIV[19] [20]. Those with a current inpatient commitment should undertake at least 2 inpatient PAs/week, not all of which need be for HIV patients.

#### *3.1.4. Non-medical specialists*

Standards, roles and competencies should be defined for clinical specialists in HIV nursing, pharmacy and other relevant disciplines.

### 3.2. Rationale

A recent large clinical review in the US indicates that clinicians who manage larger numbers of HIV patients and self-identify as "expert" in HIV adhere more closely to guidelines and use ART more appropriately, but found no difference in quality of care delivered by "expert" general physicians and by infectious diseases specialists[21]. Similarly a Canadian study found patients' adherence to ART was associated with their physicians' experience of HIV care[22] . These studies confirm evidence from earlier in the course of the epidemic, that clinician experience of caring for people with HIV/AIDS, rather than formal specialty, is a significant determinant of quality of care.

However, the core clinical skills needed for HIV inpatient care include specific expertise both in HIV-related disease and the general care of very sick patients whose condition may rapidly deteriorate and become unstable with life-threatening complications such as sepsis, renal failure or respiratory failure. Clinicians providing planned HIV inpatient care directly, and advising colleagues who may provide such care in emergencies (eg for previously undiagnosed patients) therefore need a solid grounding in and ongoing commitment to acute medicine.

The Diploma in HIV Medicine of the Worshipful Society of Apothecaries of London has been developed as a qualification to demonstrate competence in the medical management of patients with HIV, recognising that the workforce requirement for such clinicians is too small to justify a separate specialist advisory committee and examination under the auspices of the Royal College of Physicians. In addition to the examination itself, a pre-requisite for taking the Diploma is to have had regular post-qualification clinical contact with HIV medicine over a two year period, including experience of both inpatient and outpatient care. This Diploma should be recognised as the standard qualification required for all future consultants providing HIV care. BHIVA looks forward to working with relevant specialist advisory committees to enable trainees who wish to do so to gain appropriate clinical experience of HIV and to obtain the Diploma. In addition, the curriculum and format of the Diploma itself should be subject to regular review to ensure they remain fit for purpose, with advice being sought from the British Association for Sexual Health and HIV, the British Infection Society and the British HIV Association.

[19] Full-time consultants are contracted on the basis of 10 3-4 hour PAs/week of which 7.5 (7 in Wales) are clinical and 2.5 (3 in Wales) are for supporting professional activities, other NHS responsibilities and external duties. Network on-call work and advising professional colleagues about the care of individual patients count towards clinical PAs while, for example, attending network meetings, developing network protocols, CPD and clinical governance count as supporting professional activities.

[20] Limited exceptions may be necessary where geography dictates a very small network caseload (eg Northern Ireland).

[21] Landon et al. Arch Intern Med. 2005 May 23;165(10):1133-9.

[22] Delgado J, Heath KV, Yip B, Marion S, Alfonso V, Montaner JS, O'Shaughnessy MV, Hogg RS. Antivir Ther. 2003 Oct;8(5):471-8.

Under recent proposals[23], specialist certification will be subject to regular renewal based on assessment against standards set by the relevant medical Royal College. Together with the Royal College of Physicians and relevant specialty training and education committees and specialist societies BHIVA will develop appropriate methods of assessment for specialists providing HIV care. Participation in clinical governance, including via HIV network meetings, should be among the criteria for re-certification.

The National HIV Nurses Association[24] are working to develop appropriate competencies for nurses specialising in aspects of HIV care, in addition to core competencies for all nurses who come into contact with HIV patients. The HIV Pharmacy Association[25] is undertaking similar initiatives in respect of pharmacists, and further work should be encouraged in relation to other professional groups.

# 4. Records and information sharing

## 4.1. Recommendations

### *4.1.1. HIV care records*

Information relating to HIV treatment and care should be recorded in ordinary hospital records alongside that relating to any other conditions and identified by the patient's name, NHS number and date of birth.

### *4.1.2. The electronic health record*

Development of electronic health records (EHR) should proceed on the basis that HIV diagnosis and all current medication will ordinarily be included in the summary section of the EHR. The right of individual patients to opt out of record sharing or to place this information in a sealed envelope should be respected, but clinicians should not encourage this practice.

Detailed HIV care records should be developed on the basis of the same access protocols as for other chronic diseases. Priority should be given to enabling clinicians at tier 2 HIV centres providing 24 hour advice to access the detailed records of individual patients across the HIV clinical network.

## 4.2. Rationale

Although usually sexually transmitted, HIV differs from other STIs in being a long term condition potentially affecting all bodily systems. Case management requires a multi-disciplinary and at times multi-specialty approach. Even at the level of routine monitoring, some investigations (eg chest X-ray) involve hospital departments other than the specialty providing direct HIV care. For patients with more complex needs, record-sharing within the HIV network becomes a vital tool to

[23] Good doctors, safer patients: Proposals to strengthen the system to assure and improve the performance of doctors and to protect the safety of patients: A report by the Chief Medical Officer. Department of Health, July 2006. Note recommendation 31:

> *Specialist certification should be renewed at regular intervals of no longer than five years. This process should rely upon membership of, or association with, the relevant medical Royal College, and renewal should be based upon a comprehensive assessment against the standards set by that college. Renewal of certification should be contingent upon the submission of a positive statement of assurance by that college. Independent scrutiny will be applied to the processes of specialist re-certification operated, in order to ensure value for money.*

[24] http://www.nhivna.org/

[25] http://www.hivpa.org/

enable smooth transition back and forth between tier 1 and tier 2 services according to current clinical need. This requires considerable new IT development.

Currently there is no consistent practice as to how HIV care records are held even within individual providers – at some centres HIV care records are integrated with main hospital notes while in others they are held separately in GUM records identified by the patient's clinic number rather than name. This reflects historical practice as well as concern about the particular sensitivity of an HIV diagnosis. Such secrecy may tend to reinforce stigma within health services[26], as well as carrying risk in terms of :

- Potential for pathology/radiology requests and results going astray
- Inappropriate care and/or drug interactions if the patient also receives care from other departments where his/her HIV status is not known.

In view of these issues, BHIVA believes information relating to ongoing HIV care should be managed similarly to other chronic long term conditions. This requires strong assurances as to the confidentiality of health records in general, backed by robust security and information governance arrangements. In particular, for HIV status and medication to be included in the summary EHR on the national spine, which is ultimately desirable, systems must ensure that every instance of inappropriate access to information will be actively identified and acted upon. Role-based access protocols which offer tiered access to clinical and administrative information for different groups of staff are also important[27]. Opt-outs from information-sharing will remain necessary for individuals with particular needs or concerns, eg health workers who are themselves HIV positive.

Information regarding a patient's sexual history (including circumstances of acquisition of HIV) and other STIs may be stored separately in genitourinary medicine records.

It should not be assumed that electronic information storage and communication are inherently less secure than more traditional methods. Many patients welcome receipt of information via email or SMS and this can be more confidential than a hospital envelope arriving on the doormat where it is visible to other household members. Patient choice in this area should not be restricted.

# 5. The patient journey

## 5.1. Recommendations

### *5.1.1. HIV testing and diagnosis*

Moves towards an "opt-out" basis for HIV testing in GU and all relevant clinic settings should be accelerated. Alternative sites for HIV testing, including voluntary sector provision, should be expanded.

All general practices and acute medicine services should provide direct testing for diagnosis of patients with symptomatic disease which may be HIV-related. HIV testing should be recommended for patients with presenting conditions which are epidemiologically associated with HIV but which frequently occur in HIV uninfected individuals, in addition to those with recognised indicator diseases.

[26] *"I think we do have to tackle the continued stigma about stigma, by which I mean the worry about confidentiality which often prevents record sharing, it prevents people being offered HIV testing in the first place and I think we have to work on that a lot more."* Gus Cairns, at 24 July 2006 workshop.

[27] Concerns are often expressed about general practice receptionists having unnecessary access to clinical information.

### *5.1.2. Assessment after diagnosis of HIV*

All patients should be assessed within HIV services within two weeks of a positive HIV test result, irrespective of the place of testing. 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 tier 1 HIV outpatient services. However, if HIV is diagnosed during the course of an acute medical inpatient admission advice must be sought immediately from a consultant qualified to provide tier 2 HIV inpatient care. Consideration must be given to transferring the patient to the tier 2 HIV inpatient centre.

### *5.1.3. First-line ART prescribing*

Initiation of first line ART falls within the scope of tier 1 outpatient HIV services, but arrangements must be made through clinical networks for 24 hour access to HIV specialist consultant advice, typically from a tier 2 provider. Patients starting ART for the first time must be given information on how to seek such advice if needed (eg, attend A&E and give telephone number to staff there). Clinical networks should develop protocols for ART initiation, including patient education and support and the appropriate choice of drugs.

### *5.1.4. Patient monitoring*

Monitoring of patients with uncomplicated asymptomatic HIV infection, on or off ART, forms part of tier 1 outpatient HIV services.

### *5.1.5. Changing ART for reasons other than failure*

Uncomplicated changes of ART in patients with undetectable viral load and no history of drug resistance (eg for minor toxicity, patient choice or treatment simplification) form part of tier 1 outpatient HIV services. Clinical networks should develop protocols for appropriate choice of therapy in such circumstances.

### *5.1.6. Failure of ART*

All patients who fail to achieve or maintain virological suppression on ART should be assessed jointly between tier 1 and tier 2 providers, following which ongoing care will usually fall within the scope of tier 1 outpatient provision.

### *5.1.7. HIV drug resistance*

All patients testing positive for HIV resistance to any ART drug should be assessed jointly between tier 1 and tier 2 providers. Ongoing care will usually fall within the scope of tier 1 outpatient provision, but tier 2 advice should be sought for all subsequent changes in therapy for patients who have ever shown resistance to any ART drug (including changes for toxicity in the absence of new resistance or failure).

### *5.1.8. Pregnancy and delivery*

Normal pregnancy and delivery in women with uncomplicated HIV infection should ordinarily be managed within generic midwifery/obstetric services, with support from HIV liaison midwifery. Provision of ART falls within the scope of tier 1 HIV outpatient services but the birth plan should be developed in consultation with tier 2 services.

### *5.1.9. Acute illness requiring in-patient care*

Other than in exceptional circumstances, patients who need in-patient care for opportunistic illnesses, HIV-related tumours or other serious HIV-related disease should be admitted to a tier 2

HIV inpatient centre under the care of a consultant specialising in HIV inpatient care, or to the relevant tertiary service in liaison with tier 2 HIV services.

Admission under general acute medical care may be considered for patients with non-opportunistic conditions (eg bacterial pneumonia) and otherwise uncomplicated HIV infection. If such patients have not shown a good response to treatment within 24-48 hours of admission, advice must be sought from a tier 2 HIV inpatient centre, and transfer must be considered.

#### *5.1.10. Hepatitis B or C co-infected patients*

Management of patients co-infected with HIV and hepatitis B or C should be undertaken by the appropriate designated tier 2 specialised provider, unless a specialist hepatology service is available at the tier 1 outpatient HIV provider.

#### *5.1.11. Tuberculosis*

Any form of active tuberculosis in an HIV patient requires joint assessment by the lead tuberculosis centre and the appropriate designated tier 2 HIV specialised provider. Depending on local protocols and the outcome of this assessment, ongoing care for some patients may be provided through tier 1 outpatient services.

#### *5.1.12. Lymphoma or suspected lymphoma*

The care of patients with diagnosed or suspected lymphoma, of any type, should be transferred to the appropriate designated tier 2 HIV specialised provider.

#### *5.1.13. Kaposi's sarcoma*

The care of patients with diagnosed or suspected Kaposi's sarcoma should be transferred to the appropriate designated tier 2 HIV specialised provider.

#### *5.1.14. Significant renal dysfunction*

The care of patients with significant renal dysfunction should be transferred to the appropriate designated tier 2 HIV specialised provider.

#### *5.1.15. Step-down*

Local network protocols must include explicit arrangements for transfer from tier 2 HIV providers or other tertiary/quaternary care to tier 1 HIV outpatient services when the patient's condition no longer requires more specialised care.

### 5.2. Rationale

#### *5.2.1. HIV testing and diagnosis*

Late diagnosis is a major contributor to HIV-related morbidity and mortality. The one single change that could have the greatest impact on HIV outcomes would be to recognise the infection earlier in its course. The aim should be to move towards a situation where the vast majority of cases are diagnosed before the onset of ill-health, to facilitate planned and effective case management.

Currently, GPs and other clinicians frequently fail to recognise when patients present with minor or treatable illnesses HIV-related illnesses (eg skin conditions, chest infections), with the result that patient remains undiagnosed until a major opportunistic illness occurs. Although the UK prevalence of HIV is insufficient to justify general population screening, routine testing of patients with these early sentinel conditions (most of whom will be uninfected) is a reasonable strategy for preventing more serious AIDS-indicator diseases.

HIV testing should also be readily accessible on request and promoted to high prevalence groups including gay men and black-Africans. At present, long waits for GUM clinic appointments inhibit people at risk from seeking testing voluntarily. Both statutory and community/voluntary providers have a major role in making testing easy to obtain.

See also: Royal College of Physicians. *Concise guidance to good practice number 3: HIV testing for patients attending general medical services.* 2005.

#### *5.2.2. Assessment after diagnosis of HIV*

All patients with newly diagnosed HIV infection are likely to be worried. Currently a significant proportion have advanced immuno-suppression with a high short-term risk of symptomatic disease, though it is hoped that this will reduce through wider access to testing earlier in the course of infection. Prompt specialist assessment is therefore warranted and a two week target is appropriate, in line with that for suspected cancer patients.

At present late diagnosis during acute illness accounts for a substantial proportion of HIV-related deaths. Some of these deaths are medically unavoidable in that they reflect very late presentation by the patient in a moribund state. However, many people who survive acutely life-threatening presentations of HIV disease go on to enjoy excellent lifespan and quality of life on HAART, so optimum medical care is imperative to maximise the chance of initial survival. Hence immediate specialist advice from a tier 2 HIV centre is needed when HIV is diagnosed during acute illness. On successful discharge following the acute episode, most such patients will prefer to attend local outpatient HIV services for ongoing care.

#### *5.2.3. First-line ART prescribing*

Patients starting ART for the first time can be at risk of adverse effects including potentially life-threatening immune reconstitution inflammatory syndrome or drug hypersensitivity reactions. Prompt access to specialist advice is needed to manage these risks.

Many such patients will be anxious and a high proportion will experience adverse effects which, although not medically serious, may undermine adherence. Specialist advice and reassurance to support patients in establishing good adherence from the outset may impact on the long term success of therapy.

#### *5.2.4. Failure of ART*

Specialist assessment is needed to investigate adherence or other possible reasons for failure and to advise on the next-line regimen. Increasing drug resistance is likely to result from poor choice of next regimen and/or failure to address adherence or absorption problems, which will prejudice the long term effectiveness of therapy and increase the likelihood of further failure leading to declining health status, and need for expensive salvage drugs.

#### *5.2.5. HIV drug resistance*

Specialist assessment is needed to investigate reasons for the development of resistance and to advise on future regimens. Resistant virus may be “archived” such that it will rapidly reappear under drug pressure. Hence specialist advice is needed for all drug changes in a patient who has demonstrated resistance at any time, whether or not resistance is currently detectable.

#### *5.2.6. Acute illness requiring inpatient care*

Specialists continue to report poor outcomes associated with inpatients being managed locally by general physicians with input/advice from an outpatient HIV clinician who does not personally have a regular inpatient commitment. This is also inefficient as calling an outpatient consultant to the wards can be highly disruptive to busy clinic schedules. Hence the tier 2 HIV centre should be the

main resource for managing patients needing inpatient care, both directly by admission to the tier 2 HIV centre and via network advice from the consultant on call.

Some patients will continue to be admitted locally under the care of general physicians (eg those with previously undiagnosed HIV). The key to effective management in such circumstances is to seek advice promptly from the tier 2 centre, and to consider early transfer if there are signs that the patient is not responding well to treatment. This minimises the risk of the patient's condition deteriorating to such an extent that transfer becomes medically unsafe or involves costly ITU to ITU procedures with monitoring by an anaesthetist during the transfer. Inevitably, however, there will some patients who present so late and deteriorate so rapidly that ITU admission is needed before transfer can be arranged – these are typically the patients at imminent risk of death and thus in most critical and urgent need of tier 2 expertise in acute HIV medicine. To manage such cases network arrangements must be in place either for ITU to ITU transfer to the tier 2 HIV centre or for tier 2 consultant outreach to the centre where the patient has been admitted.

#### *5.2.7. Step-down*

Unnecessary over-centralisation of care risks undue pressure on capacity at HIV referral and inpatient centres and causes resentment among outpatient providers; it is as detrimental to efficient networks and good case management as under-specialisation. Not all patients are suitable for step-down – eg those with malignancies are likely to require ongoing tertiary care – but most prefer to attend outpatient HIV services for ongoing care.

# 6. Implementation and audit

## 6.1. Implementation

This document is currently in draft and will be refined through a consultation process with a view to final joint publication by BHIVA and the Royal College of Physicians at the end of 2006. BHIVA expects then to work with clinicians, commissioners, SHAs, the Department of Health and other stakeholders towards implementation of the recommendations.

## 6.2. Audit

Audit is a necessary part of implementation, to assess the extent to current services meet recommended standards and identify where change is needed. However, it is impracticable to audit and regularly re-audit against all recommendations in this document and in clinical guidelines. Hence BHIVA would particularly welcome views on the key criteria which should be rigorously audited at the national level.

#### *6.2.1. Proposed key criteria to be audited nationally*

*Managed clinical networks*

Proportion of centres participating in the BHIVA national audit programme (or otherwise known to provide ongoing care to adults with diagnosed HIV) able to:

1. name the HIV clinical network of which they are a member
2. self-describe either as providing tier 1 outpatient services or as providing tier 2 services including complex and inpatient care
3. if tier 1, name one or more tier 2 centres to which they would refer patients requiring complex care.

Direction: aim to maximise. Rationale: Basic indicator of network participation.

Proportion of centres participating in the BHIVA national audit programme who report sharing and discussing their results within their clinical network. Direction: aim to maximise. Rationale: Provides evidence of network-level engagement in clinical governance.

*HIV testing/diagnosis*

Proportion of newly diagnosed HIV patients whose CD4 count is below 200 cells/µl when measured for the first time after testing positive for HIV. Direction: aim to minimise. Rationale: Need for earlier diagnosis to institute case management and prevent symptomatic illness.

*Initiation and use of ART*

Proportion of patients starting ART for whom an HIV drug resistance test result has been obtained. Proportion of patients starting ART for the first time whose hepatitis B status is either immune or has been determined within preceding year. Proportion of diagnosed HIV patients whose CD4 count has ever been under 200 cells/µl who are currently on ART. Proportion of patients starting ART for the first time who attain an undetectable HIV viral load within six months. Direction: aim to maximise. Rationale: These key indicators reflect compliance with BHIVA clinical guidelines.

### *6.2.2. Criteria for audit by managed clinical networks*

The following additional criteria are suggested to enable clinical networks to audit their own performance in specific areas. These should be read alongside BHIVA's clinical guidelines which include auditable criteria for interventions for the individual patient.

*General practice*

Among HIV patients under care, proportion a) known to be registered with a GP and b) whose GP has been informed of their HIV status. Direction: aim to maximise. Rationale: Importance of effective GP care in liaison with HIV services.

*HIV testing/diagnosis*

Among newly diagnosed HIV patients, proportion who had previously presented to general practice or acute medical services within the preceding year with sentinel conditions and had neither been tested for HIV nor had a documented refusal of consent for such testing. Direction: aim to minimise. Rationale: Indicates previous missed opportunity for diagnosis.

*Assessment after diagnosis of HIV*

Among newly diagnosed HIV patients, proportion assessed within a specialist HIV service within two weeks of positive test result. Direction: aim to maximise. Rationale: Need for prompt assessment of newly diagnosed HIV patients.

*Appropriate use of tiered services*

Among HIV patients receiving care from a provider of tier 2 services, proportion who are identifiable as being in receipt of either tier 1 or tier 2 services. Direction: aim to maximise. Rationale: Audit of network effectiveness and use of resources requires patients who receive tier 1 services from a tier 2 provider to be distinguishable from patients who receive tier 2 services.

Among patients with diagnosed HIV infection across a managed clinical network, proportion who are receiving a level of care (tier 1 or tier 2) appropriate to their current clinical needs. Direction: aim to maximise. Rationale: Improve service uptake and appropriate use of different tiers of provision.

*Failure of ART*

Among patients starting ART, proportion who have neither achieved undetectable HIV viral load (VL) nor been assessed at a tier 2 HIV centre within 6 months of starting ART. Direction: aim to

minimise. Rationale: Need for prompt specialist assessment of the reasons why patient has failed to achieve VL undetectability.

Among patients on ART with previously undetectable VL who have two consecutive VL results over 400 copies/ml, proportion who have not been assessed at a tier 2 HIV centre within 3 months of the first such result. Direction: aim to minimise. Rationale: Need for prompt specialist assessment of the reasons for VL rebound.

*HIV drug resistance*

Among patients with positive resistance test results, proportion being assessed at a tier 2 HIV centre within six weeks of the date the sample was taken. Direction: aim to maximise. Rationale: Need for specialist assessment of reasons for resistance and advice on appropriate regimen.

Among patients who have ever shown evidence of HIV resistance, proportion of changes of ART therapy made in consultation with a tier 2 HIV centre. Direction: aim to maximise. Rationale: Need for specialist advice on appropriate regimen.

*Acute illness requiring inpatient care*

Among HIV in-patients admitted under general acute medical care, proportion transferring to tier 2 HIV centre more than 48 hours after admission. Direction: aim to minimise. Rationale: Within 48 hours it should be apparent whether the patient is responding well to therapy, and can continue to be managed locally, or whether transfer for more specialised care is indicated.

*Patients with active TB, or with hepatitis B or C co-infection, lymphoma, KS or significant renal dysfunction*

Among all relevant patients across network, proportion managed in accordance with recommendations. Direction: aim to maximise. Rationale: These are complex conditions requiring more specialised care, including joint assessment/management with other specialties.

*Step-down*

Among all patients currently receiving tier 2 or other specialised care, proportion whose suitability for planned step-down has been reviewed and assessed within the last three months. Among those assessed as suitable for step-down, proportion for whom step-down is proceeding on schedule. Direction: aim to maximise. Rationale: Avoid unnecessary over-specialisation of care.

*Death of people infected with HIV*

Among all deaths of adults with HIV, proportion formally reviewed within one year of death. Direction: aim to maximise. Rationale: Improve understanding of potentially avoidable factors leading to mortality.

Among deaths of adults with HIV occurring during inpatient care other than at a designated tier 2 HIV centre, proportion formally reviewed at a meeting of the full managed clinical network within one year of death. Direction: aim to maximise. Rationale: Review at the network level facilitates discussion of whether death might have been prevented if advice had been sought more promptly from specialists at the tier 2 HIV centre and/or if the patient had been transferred to the tier 2 HIV centre.

# 7. Annex 1: Glossary

ART: Anti-retroviral therapy using combinations of specific drugs which suppress replication of HIV.

BHIVA: British HIV Association.

CCT: Certificate of Completion of Training (formerly CCST, Certificate of Completion of Specialist Training). Advanced post-graduate qualification in an individual specialty typically completed 5 or more years after qualifying as a medical practitioner. Ordinarily required for entry to the Specialist Register, which is in turn required for eligibility to apply for NHS consultant posts.

Consultant: Except where nurse consultants are mentioned explicitly, the word "consultant" is used in this document to refer to medical consultants.

GUM: Genitourinary medicine. GUM is unusual among specialties in having two routes of entry; trainees holding either the MRCOG or the MRCP may enter higher specialist training leading to the CCT in GUM.

HIV: Human immunodeficiency virus.

JCHMT: Joint Committee on Higher Medical Training, which oversees medical training and works with specialist advisory committees for each specialty to develop their curricula for training leading to the CCT.

MRCOG: Membership of the Royal College of Obstetrics & Gynaecology (basic post-graduate qualification typically completed two years after qualifying as a medical practitioner).

MRCP: Membership of the Royal College of Physicians (basic post-graduate qualification typically completed two years after qualifying as a medical practitioner).

PCT: Primary Care Trust.

PMETB: Postgraduate Medical Education and Training Board, a statutory body which promotes, sets and enforces standards for medical training.

SHA: Strategic Health Authority

STI: Sexually transmitted infection.

TB: Tuberculosis.

# 8. Annex 2: Geographical caseload data

## 8.1. Survey of Prevalence of Diagnosed HIV Infection and Disease (SOPHID) 2004

| Strategic Health Authority (to 2006) | People seen for medical HIV care within SHA | SHA residents seen for HIV care anywhere in England, Wales or Northern Ireland |
|---|---|---|
| Avon, Gloucestershire and Wiltshire | 713 | 742 |
| Bedfordshire and Hertfordshire | 808 | 1134 |
| Birmingham and the Black Country | 1393 | 1312 |
| Cheshire & Merseyside | 683 | 641 |
| County Durham and Tees Valley | 156 | 202 |
| Cumbria and Lancashire | 545 | 638 |
| Dorset and Somerset | 350 | 437 |
| Essex | 445 | 616 |
| Greater Manchester | 2294 | 2087 |
| Hampshire and Isle of Wight | 532 | 667 |
| Kent and Medway | 377 | 498 |
| Leicestershire, Northamptonshire and Rutland | 815 | 871 |
| Norfolk, Suffolk and Cambridgeshire | 703 | 711 |
| North and East Yorkshire and Northern Lincolnshire | 232 | 272 |
| North Central London | 5536 | 3931 |
| North East London | 3313 | 4031 |
| North West London | 7882 | 4932 |
| Northumberland, Tyne and Wear | 519 | 448 |
| Shropshire and Staffordshire | 278 | 342 |
| South East London | 4005 | 5400 |
| South West London | 1906 | 2367 |
| South West Peninsula | 323 | 375 |
| South Yorkshire | 511 | 475 |
| Surrey and Sussex | 1849 | 2077 |
| Thames Valley | 1124 | 1292 |
| Trent | 701 | 780 |
| West Midlands South | 475 | 535 |
| West Yorkshire | 927 | 939 |
| Wales: Mid & West | 139 | 186 |
| Wales: North | 97 | 137 |
| Wales: South East | 386 | 353 |

| | | |
|---|---|---|
| Northern Ireland | 248 | 239 |
| England, SHA of residence unknown | | 17 |
| Wales, SHA of residence unknown | | 1 |
| Country of residence unknown | | 490 |
| Other/abroad | | 90 |
| **Overall Total** | **40265** | **40265** |

## 8.2. SOPHID and other data mapped to new SHAs (post 2006)

| SHA or country | Total HIV patients under care in 2004 | 2004 population mid-year estimate | Estimated HIV patients under care in 2004 per 100,000 population |
|---|---|---|---|
| East Midlands | 1516 | 4,280,000 | 35 |
| East of England | 1956 | 5,491,000 | 36 |
| London | 22642 | 7,429,000 | 305 |
| North East | 675 | 2,545,000 | 27 |
| North West | 3522 | 6,827,000 | 52 |
| Northern Ireland | 248 | 1,710,000 | 15 |
| South Central | 1656 | 3,922,000 | 42 |
| South East Coast | 2226 | 4,188,000 | 53 |
| South West | 1386 | 5,038,000 | 28 |
| Wales | 622 | 2,952,000 | 21 |
| West Midlands | 2146 | 5,334,000 | 40 |
| Yorkshire and The Humber | 1670 | 5,039,000 | 33 |
| Scotland | 1911 | 5,078,000 | 38 |
| Total | 42176 | 59,833,000 | 70 |

# 9. Annex 3: Process

This document has been prepared by a small core operations group, working under the auspices of the BHIVA Audit and Standards Sub-Committee. Membership of the group is as follows:

- Professor Margaret Johnson (chair), BHIVA chairperson
- Hilary Curtis PhD, BHIVA audit and standards co-ordinator
- Nathaniel Ault, Nurse Consultant, Barts and the London NHS Trust
- Gus Cairns, UK Coalition of People Living with HIV and AIDS
- Dr Colm O'Mahony, Consultant Physician in Sexual Health, Countess of Chester Hospital NHS Foundation Trust
- Dr Celia Skinner, Associate Clinical Director HIV medicine, Barts and the London NHS Trust
- Paul Ward, Deputy Chief Executive, Terrence Higgins Trust
- Rosy Weston, Senior Principal Pharmacist, St Mary's NHS Trust.

The process to date is that an initial draft was prepared on the basis of consultation with a limited number of selected individuals. That draft was opened to a wider consultation at a stakeholder workshop held at the Royal College of Physicians on 24 July 2006. The document was substantially revised in the light of discussion at the workshop and other input from interested parties, and has now been opened for general public consultation. Responses are welcome up until 7 November 2006 and can be submitted online via http://www.bhiva-clinical-audit.org.uk or sent to Hilary Curtis, hilary@regordane.net.

A full list of those participating in the consultation process will be appended to the final published report, unless individuals ask for their names to be withheld.