

Standards for NHS hospital HIV services

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Published by BMAIDS Trading Ltd on behalf of:

BMA Foundation for AIDS

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Bristol-Myers Squibb Pharmaceuticals supports the work of the BMA Foundation for AIDS. North Thames NHS Regional Office supports the work of Jane Carrier at the Centre for Research on Drugs and Health Behaviour. This project was additionally supported by the Inner London HIV Health Commissioners Group.

ISBN 0 7279 1416 2

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1 Introduction

1.1 Background and purpose

The purpose of this document is to define standards for the quality of hospital based care for people living with HIV. It is based upon a lengthy and inclusive process of consultation which is described in detail below, indicating that the standards which it proposes reflect a broad consensus among many of the professional groups who are involved in providing or commissioning HIV care, as well as people living with HIV. The document is being circulated to HIV services, health authorities and advocacy and self help organisations, all of which will be able to make use of the standards for different purposes. While this is a final report, it is recognised that HIV/AIDS is a rapidly developing field and that the process of implementing the standards will yield new insights. Hence the standards themselves may require revision at a later date as circumstances change.

The project to develop shared standards for HIV care has been carried out by the BMA Foundation for AIDS and the Centre for Research on Drugs and Health Behaviour, Imperial College School of Medicine, with the support of the Inner London Health Authorities, North Thames Regional Office and Bristol-Myers Squibb Pharmaceuticals¹. It emerged from two earlier initiatives, *Developing the Agenda*², which aimed to identify the issues and dilemmas facing the HIV field following the introduction of combination therapy and *Developing Service Networks for HIV Care in London*³, which explored how the organisation of acute care in the capital could be strengthened. The service networks project concluded that acute HIV care in London could be organised using a geographically based network model, similar to that recommended for cancer services by Calman/Hine. It also recommended that activities within each network should be shaped by explicit standards for HIV care.

This shift away from the organic model of service organisation which has characterised HIV care, towards greater role definition and consistency of care is in line with policy developments within the wider NHS. The standards contained in this document will act as an effective tool in developing network arrangements.

Throughout the process for developing the standards, it became clear that the principle of networking is widely supported by clinicians, commissioners and representatives of people with HIV.

While acknowledging the need for flexible local implementation, the level of interest which this initiative has attracted indicates that it is likely to influence the forthcoming national HIV/AIDS strategy as it relates to service organisation in England. It may also form a useful starting point for discussion regarding service models in Wales, Scotland and Northern Ireland.

1.2 The wider context

The development of quality standards for HIV services is consistent with wider NHS policy initiatives. The NHS White Paper emphasises consistency and quality of care and presents the recent reconfiguration of cancer and paediatric intensive care services as future models of service organisation. In both cases the reconfiguration of care was driven by clear, agreed service standards.

The White Paper also introduces a range of new structures and mechanisms which aim to improve quality of care. These are described in more detail in the document *A First Class Service - Quality in the New NHS*⁴. The role of the National Institute for Clinical Excellence will be to assess the effectiveness of new drugs and interventions and to issue NHS-wide guidance on their use. National Service Frameworks will be developed on a rolling programme for many groups of patients. Their role will be to define models of care, in particular clarifying which elements of care are provided by each service and how patients move between providers, as in the Calman/Hine recommendations.

The increasing emphasis on clinical governance⁵ also forms a central part of the wider context. The development of clinical networks, with peer review and multi-centre audit, forms a central feature of clinical governance. Trusts will have an explicit responsibility to ensure that standards are met, while professional self regulation will be strengthened and all staff will be encouraged to keep their skills up to date through participation in lifelong learning.

Similarly, the consultation paper on *Commissioning specialised services* focuses on developing service models for specific patient groups via regional or national commissioning arrangements. The announcement that specialised aspects of HIV and AIDS will be included in specialised commissioning arrangements offers a pathway for planning these services across areas wider than individual health districts.

These varied developments are linked by a concern to reduce inconsistencies of care and to protect users of services by ensuring that high standards are maintained. Against this background, the development of standards for HIV care appears timely and offers the HIV field an opportunity to demonstrate its ability to take on new agendas and embrace change for the benefit of people living with HIV.

The developments proposed in this document will demand that all members of the clinical network adopt more explicit roles in relation to each other and learn to operate in what, for some, will be new ways. In addition, explicit quality standards should help in ensuring continuity of provision and planned service restructuring in the context of likely changes to the basis for allocating funding for

HIV treatment and care⁶.

While this project focusses on hospital-based services, the partnership agenda set out in the recent white paper *Partnership in action* emphasises the desirability of greater integration between health and social care. As noted in section 3.2.4, HIV care has traditionally been characterised by collaborative and interagency working. It is hoped that this approach will be strengthened by expanding the boundaries of the network model proposed in this document.

1.3 Rationale and ethos

The starting point for this project is to ensure that people living with HIV have access to a consistently high standard of care regardless of where they live and/or which providers they use. People living with HIV have diverse needs and the project aims to ensure that these are met as consistently as possible. The introduction of combination therapy has highlighted inconsistencies in the provision of care.

A high standard of care may be defined in terms of the features defined by Maxwell⁷ which include effectiveness, efficiency, accessibility and acceptability. The criterion of effectiveness implies that service developments should, to the greatest extent feasible, be evidence-based. Evidence may take a variety of forms, ranging from results of controlled trials, through other objective data, to the considered opinion of suitable experts, though service user views on effectiveness are also important.

Where objective data exists, clearly this should form the basis of standards development. However, in general it is difficult to generate such data on the effectiveness of different models of service organisation. This difficulty has been recognised by the NHS Executive, which is about to establish an R&D programme focussed on this area.

In terms of HIV services, there is evidence to suggest that better outcomes are achieved in centres with greater experience in treating people with HIV, both in the UK⁸ and the USA⁹, though caution is needed in interpreting this data. Existing evidence relates primarily to the period before the introduction of HAART, which has fundamentally changed our definition of desirable treatment outcomes. Outcomes are increasingly dependent on the availability of appropriate monitoring, prescribing and adherence support. There is no clear data addressing the effectiveness of networking and collaboration between centres with different levels of experience. However, this is a model which is widely accepted as appropriate and effective for the delivery of complex specialised services, as evidenced for example by the Calman/Hine report on cancer services¹⁰ and the recent review of paediatric intensive care¹¹.

The criterion of acceptability implies a central role for people living with HIV in defining quality standards, both in terms of the range of services provided and the manner in which they are

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delivered. This has informed our project in terms of the range of stakeholders consulted, but should

2 Project description

also shape the implementation process. Acceptability to professionals is also of key importance in ensuring the practicability of standards, and implies a need for flexibility.

2.1 Standards development

The aim of the project has been to develop widely agreed standards for hospital-based HIV care. It focuses on the organisational and infrastructural aspects of care and does not attempt to develop clinical guidelines, as other organisations have already successfully developed work in this area. It is hoped that the standards will apply across England and the development process reflects this aspiration. While the project addresses the interface between the hospital setting and community based services, it does not seek to develop standards for primary or community care and voluntary services. As such, this document is a starting point and further work will be required to explore how these services can be integrated within networks. Early discussions on the relationship of the voluntary sector to the hospital networks described in this document indicate the willingness of many organisations to operate within a network model and it is hoped that future work will explore this area. The Terrence Higgins Trust is currently leading a national initiative to develop standards for some aspects of voluntary sector care and liaison across the two projects will ensure complementarity.

The structure of the project has been informed by the wish to involve as many stakeholder groupings as possible in developing the standards, including people living with HIV and those who provide and commission their care. A list of the individuals and groups who have contributed to the process is appended as Annex 4.

The development process has been as follows:

- multidisciplinary preliminary workshop, which defined:
 - the type of standards which were likely to be needed
 - the broad areas they should cover
 - the groups who should be involved in the process
- series of individual and group meetings to develop the content in greater detail and to gain support for the principles

3 Issues relating to development of standards

- production of a first draft standards document which was circulated widely for comment
- on the basis of the consultation, production of a second draft for discussion at a stakeholder workshop held on 16 November 1998, which also considered steps towards standards implementation
- production and wide dissemination of this final version, amended to reflect discussion at the workshop
- production of a draft implementation framework, reflecting ideas generated at the workshop.

2.2 Implementation

The implementation of the service standards generated by this project may involve a range of parallel processes:

- possible incorporation within the forthcoming national HIV/AIDS strategy
- development of service networks and protocols through local and regional stakeholder negotiations; there are plans to facilitate this work both within and outside London
- other implementation work will fall within the development of specialised commissioning and clinical governance mechanisms flowing from the NHS White Paper.

3.1 Features of HIV

Standards need to take account of the unique combination of features which characterise HIV care, including:

- A clear public health rationale for continuing open access at the point of entry to HIV care, while recognising that a significant proportion of individuals present via routes other than GUM, such as acute medicine
- Focal epidemiology, with substantially higher prevalences in London and other urban centres
- Cultural appropriateness for population groups which are particularly affected by HIV

- Well-developed and effective multisectoral working.

3.1.1 Open access

GUM services continue to play a critical role both in prevention of HIV infection and diagnosis as a point of entry to ongoing care. Open access is one of the features underpinning the effectiveness of this role, as it ensures accessibility and confidentiality. Within the service network model proposed below, most GUM services will also be key service providers to people with HIV. Any reconfiguration of HIV care must not be allowed to undermine the existing network of GUM services.

3.1.2 Local variability

In order to develop standards which are broadly applicable across the whole of England, it is necessary to take account of both geographical factors such as ease of travel and population density, and the focal epidemiology of HIV infection. This diversity implies that any model of service organisation must be sufficiently flexible to accommodate local circumstances. For example, it is not possible to set a network size or population base which would be appropriate for the whole country, as the composition of local networks will be influenced by such factors as caseload, existing patient flows and geography.

The principle of networking should form the basis of service planning across the country. However, it may not be possible to apply all the detailed standards in the most geographically dispersed areas of the country where the prevalence of infection is also particularly low. Where variation from the standards occurs, it will be important to demonstrate that this is both necessary and within limits of acceptable risk.

3.1.3 Cultural appropriateness

HIV primarily affects defined population groups such as gay men, injecting drug users and people of African origin, including children and families. All of these groups may experience discrimination or social exclusion. This has wide-ranging implications for the way in which care is delivered, for example:

- staff recruitment and training to ensure non-judgmental, informed and supportive care
- location, environment and marketing of clinical services
- cultural appropriateness of written material and visual images for different patient groups
- availability of information in different languages and formats, use of advocates and interpreters.

In particular, it is important to recognise that the three main groups affected by HIV/AIDS have different needs and settings which are highly appropriate for one may be less suitable for others. Hence local services need to be designed with the needs of all the locally affected groups in mind. In addition the geographical mobility of groups such as refugees and drug users needs to be incorporated into service delivery. Health care professionals should endeavour to locate medical information on these patients from prior health contacts to ensure continuity of treatment.

3.1.4 Multisectoral working

HIV care has been characterised by collaborative models of service delivery involving hospital, community care, primary care, local authority, voluntary sector and self-help providers. Networks of hospital-based care should be developed in such a way as to promote effective linkages with and between other providers.

3.2 Types of standard

Standards may have a number of functions:

- defining the baseline/minimum below which no service should fall
- indicating the direction for future service development and reconfiguration
- presenting an ideal or "gold standard" to which services should aspire.

In terms of this project, the aim has been to define baseline/minimum standards for different elements of service provision, together with some developmental standards indicating directions for the future, while distinguishing clearly between these two types of standard. The developmental standards, which may, in future be seen as baseline, are included as footnotes.

It is important also to consider the ownership of standards and the stimulus for their production. In some cases, standards have been developed as a central initiative in response to perceived major failings of existing services. Such failings are much less apparent in relation to HIV. It is therefore possible for standards to be developed through an evolutionary inclusive approach which builds on existing good practice and, hopefully, ensures wide ownership of the standards among the various stakeholders involved. Such ownership should in turn ensure a commitment to implement the standards via local negotiation.

3.3 Tensions inherent in developing service organisation standards

3.3.1 Accessibility and consistency

There is an inherent tension between consistency and ease of access to specialised clinical services.

While standards aim to promote consistency, a rigidly prescriptive approach may be incompatible with reasonably local care provision especially in geographically remote and low prevalence areas.

However, consistency is not synonymous with uniformity, and flexibility in implementing standards can be used as a means towards the goal of consistently high quality of care. This report aims to strike a reasonable balance in accepting the need for some local flexibility, but a better understanding of patients' willingness to travel and their perceptions of the trade-off between accessibility and consistency would be helpful in its implementation.

3.3.2 Resource implications

Similarly, there is an tension between the desire for high standards to ensure optimal patient care and the recognition that available resources are limited. If baseline standards are perceived as “too high” in the sense of being costly to implement, then it will be difficult to secure the support of funders, commissioners and trust managements. Although inherent in all standards development work, this issue raises particular concern in the context of the expected move from district of treatment to district of residence-based funding for HIV/AIDS treatment and care, which will shift responsibility for commissioning towards health authorities in lower prevalence areas. There are real anxieties about some of these authorities' level of commitment to and understanding of the needs of people with HIV/AIDS, although these may be partly allayed as specialised commissioning arrangements come into play.

It may be helpful to break down the likely costs of standards implementation based on networks of service providers into three main areas:

- transitional costs involved in supporting the development of networks: these costs will be higher in areas where networks are not already well-established.
- costs of care: it is not apparent that service networks will lead to higher costs for direct patient treatment and care than a more haphazard model of service delivery. There may be savings through more coherent planning of facilities and improved outcomes eg more efficient use of prescribing expertise and adherence support may help to prevent costs associated with treatment failure and viral drug resistance.

- costs of clinical governance and maintaining networks: investing staff time in quality improvement activities such as professional development and clinical audit undoubtedly has resource implications. However, these activities are expected to become mandatory throughout the NHS as part of the implementation of the White Paper, and again it is not obvious that the arrangements proposed for HIV/AIDS services in this report will be more costly than for other areas of care.

3.3.3 Relating service organisation to quality of care

This report focuses on standards for service organisation on the principle that appropriate structures are a pre-requisite for optimal care, and by analogy with other recent developments such as the Calman/Hine recommendations for cancer services and the review of paediatric intensive care. However, organisational structures such as well-functioning professional and service networks do not in themselves prove that patients are receiving high quality care. The interplay between these organisational standards and clinical indicators such as adherence to relevant guidelines should provide some greater assurance of quality. The role of audit in monitoring quality of care is extremely important. The measurement of quality remains problematic, however, and it is unclear how feasible it would be to develop standards based on direct quality indicators.

An example of this is the question of whether standards should be outcomes-based. Clearly, clinical outcomes are among the principal indicators of quality of care for people with HIV. Outcomes-based research (where available) is valuable as a basis for standards development, but there are considerable technical difficulties in using outcomes for routine monitoring of clinical performance:

- relatively few outcome measures have been defined, and data is lacking
- even if comprehensive data were available, adjustment for case mix might prove complex
- there are statistical difficulties in distinguishing between acceptable and unacceptable variations: simple "league table" approaches are liable to mislead.

Moreover, while outcomes may be the "gold standard" for measuring service effectiveness they do not necessarily reflect other dimensions of quality such as acceptability to people living with HIV. Nor does evidence that different providers show (unacceptable) differences in outcome necessarily assist clinicians and planners in identifying the reasons for the variation and how it could be rectified.

3.3.4 Professional concerns

Change tends to be perceived as posing both threats and opportunities, and the development of standards is no exception. During the course of this project it has been apparent that while clinicians are keen to ensure the best quality of care for their patients, some are also apprehensive about the impact of a more formal approach to quality and service organisation. In particular, there are concerns that over-centralisation of care may destabilise smaller units while overwhelming the major centres (at a time when HIV prevalence is increasing overall due to improved survival). While the network model of service organisation aims to avoid unnecessary centralisation, the existence of these professional anxieties raises the question of how rigorously standards should be monitored and enforced, and in particular what consequences should flow if they are not met, given that they can only be implemented with the active support and involvement of the clinicians involved. Considerable ambivalence about this has been expressed during the project, with people stating both that standards should be non-threatening, but that they must have teeth.

3.4 "Critical mass"

The "critical mass" needed to provide a comprehensive range of services is an important concept for HIV care. However it seems likely that attempting to define this in terms of caseload may not be appropriate.

It is possible that there is such a large disparity between the caseloads of the large central London centres and all others in the UK, that attempting to fix a minimum caseload which has national relevance would be extremely difficult. Critical mass can, however, be defined "backwards" in terms of levels of expertise and facilities needed to offer particular types of service within a network of collaborating providers. It is difficult for a single-handed specialist, however competent, working without junior colleagues, to provide some services because of lack of cover for 24 hour care, annual leave etc, and risk of instability if he or she moves to a different job.

3.5 Principles for effective networking

Throughout the project, there has been a clear consensus that the way forward in delivering high quality services for people with HIV lies in the development of service networks, so that no provider unit is operating in isolation. The following principles can be set out as the basis of effective networking:

- Networks should operate on a principle of subsidiarity, that is to say by providing support to local providers to enable them to offer as wide a range of services as can be achieved within limits of acceptable risk. The aim should not be to centralise all aspects of care.
- Patients should have access to the full range of services available within a network regardless of which provider they usually attend.

- There should be professional networks and skills sharing, including in some cases staff rotation, for each key discipline (eg medicine, nursing, pharmacy, psychology, dietetics, physiotherapy, occupational therapy) across the network of providers.
- Specific providers should be explicitly identified as sources of clinical leadership for the network. There are likely to be large, well resourced units, usually but not always with access to research departments.
- Patient pathways and referrals between different providers within the network should be guided by explicit protocols which are mutually agreed throughout the network.
- Flexibility should be ensured via regional and local implementation of these national principles. Network structures and/or protocols should not be imposed from above.

3.6 Terminology

Typically a network of NHS HIV service providers may consist of two or three main elements:

- A number of *out-patient HIV units*, which will provide a predominantly out-patient service. In most cases these will be located within GUM departments of DGHs, though HIV services have also developed around certain other medical specialties including ID. Some other centres may perform a similar role, for example haemophilia centres, prison medical services, and in future potentially some general practices with high HIV caseloads. The same quality standards should apply to all out-patient HIV units, regardless of the particular service configuration.
- *In-patient HIV units*, which are likely to be located at hospitals which have a wide range of investigative and treatment facilities. These units will also have their own out-patient services. The HIV provision may be based around GUM, ID and/or other relevant specialties.
- *Comprehensive HIV units* which will provide the full range of HIV treatment services but will also provide overall clinical leadership for the network including leading research, education and audit. A key element of their role will be to provide support services to other network members and to ensure the smooth operation of the network as a whole. The function will also include liaising with other comprehensive HIV units to promote consistent practice across networks.

This model of service provision is in line with the recommendations contained in the recent report *Developing service networks for HIV care in London*³.

4 Standards for service organisation and provider roles

Planned clinical management of patients known to have HIV infection should be coordinated through service networks comprising *out-patient HIV units*, *in-patient HIV units* and *comprehensive HIV units* working together within defined protocols. The description of providers as out-patient and in-patient units is partly a matter of terminological convenience. All HIV units should provide out-patient care, and this is an increasingly important element of care. However, as in-patient provision will be concentrated in units with greater involvement and expertise in HIV care, the term "in-patient HIV unit" is a convenient label for these units. Comprehensive HIV units will have an even more intensive role, providing a full range of clinical services and clinical leadership for the network. As noted above, HIV care may be based in a number of clinical settings, most commonly GUM or ID.

In most cases, a network should serve people living within a geographically coherent area covering a number of health districts. There may be some exceptions to this, eg where a non-contiguous network would better reflect existing patient preferences and/or professional links.

Although the main focus of this project is the development of standards for hospital care of patients with diagnosed HIV infection, in the interests of completeness it is important to outline the roles of other services within the NHS, partly as points of entry to ongoing HIV care. Hence this chapter proposes two types of standard:

- Basic requirements for HIV-related provision which should apply across the NHS, whether or not the unit concerned offers ongoing care for people with diagnosed HIV (sub-sections 4.1-4.7)
- Standards for units offering ongoing care for people with diagnosed HIV (sub-section 4.8 and section 5).

In addition to the standards proposed in this report, more general NHS quality standards will also be applicable to services for people with HIV, including provision of information and access to complaint procedures. All NHS services should be provided in a non-discriminatory manner with regard to cultural appropriateness for groups affected by HIV/AIDS, including gay men, drug users and ethnic minorities.

4.1 Acute hospitals (ie with accident and emergency departments)

A significant proportion of people present with symptomatic HIV disease without having previously

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been tested for HIV (or without disclosing their status), either via accident and emergency or on

referral from a GP. Emergency admission may be required in some cases (eg patients with major respiratory or neurological opportunistic illnesses) and early transfer to an in-patient or comprehensive HIV unit may not always be feasible.

Hence all acute general hospitals need to meet basic standards for the diagnosis, care and referral of such patients, and should have the following arrangements in place:

- HIV testing available at all times for diagnosis of patients presenting with possible HIV-related symptomatic disease, including tuberculosis patients, where appropriate with informed consent.
- Protocol for seeking advice from in-patient or comprehensive HIV unit re immediate management/transfer of patients presenting with serious symptomatic HIV disease.
- Protocol for referring HIV positive patients to out-patient, in-patient or comprehensive HIV units for on-going care.
- Protocol for managing needle-stick and other potential occupational exposures to HIV and providing advice and PEP where necessary.
- Protocol for managing requests for PEP following potential non-occupational exposures (in accident and emergency department).
- Sensitive and effective infection control protocols designed to protect the welfare of patients and staff while avoiding stigma.

In addition, all general hospitals should provide appropriate and non-discriminatory care for non-HIV-related needs of HIV positive patients.

4.2 General medical practices

All general medical practices should provide the following:

- Willingness to advise/recommend HIV testing when clinically indicated, including encouraging antenatal testing in line with arrangements at local maternity units.
- Advice or willingness to arrange advice on HIV prevention and safer sex.
- Willingness to provide ordinary general medical services to people with HIV and to liaise with out-patient, in-patient and comprehensive HIV units.
- Arrangements for providing HIV testing with informed consent at the practice and/or referring patients requiring testing to an out-patient, in-patient or comprehensive HIV unit.
- Alertness to possible clinical signs of HIV disease, and appropriate diagnostic testing/referral.
- If HIV testing provided at the practice, arrangements for referring HIV positive patients to out-patient, in-patient or comprehensive HIV unit and for ensuring on-going care, which may be shared.

- Arrangements for managing potential occupational exposure incidents and obtaining advice and PEP by arrangement with other suitable local services.
- Information for patients on local fixed needle exchange and GUM services.
- Sensitive and effective infection control protocols designed to protect the welfare of patients and staff while avoiding stigma.
- Clear and effective confidentiality policy which is well-communicated to patients.

4.3 General dental practices

General dental practices should offer the following:

- Willingness to provide ordinary community dentistry to patients with HIV.
- Alertness to possible oral manifestations of HIV disease, and appropriate referral to oral medicine or specialist dentistry services.
- Awareness of local network arrangements for medical HIV provision.
- Protocol for managing potential occupational exposure incidents and obtaining advice and PEP by arrangement with other suitable local services.
- Sensitive and effective infection control protocols designed to protect the welfare of patients and staff while avoiding stigma.

4.4 Maternity units

All maternity units should provide the following:

- HIV testing service in line with the recommendations of the Royal Colleges' report¹² including:
 - offering and recommending testing to all women in high prevalence areas as an integral part of antenatal care and to women at higher risk in other areas
 - accessible and appropriate information about HIV infection for all women
 - availability of testing without obstacle for all women directly through antenatal care services.
- Protocol for offering and encouraging antenatal HIV testing, with attention to cultural and language issues for ethnic minority patients. These arrangements need to be supported by appropriate staff training and to be communicated to local GPs.
- Protocol for referring HIV positive antenatal patients for specialist maternity care and HIV care, and to community or voluntary services able to provide support for families affected by HIV.
- Protocol for managing potential occupational exposure incidents and obtaining advice and PEP by arrangement with other suitable local services.
- Sensitive and effective infection control protocols designed to protect the welfare of patients

and staff while avoiding stigma.

4.5 Paediatric and child health services

A related initiative, which aims to develop standards for HIV paediatric care, including care of families, is likely to take place shortly. However, all paediatric and child health services should provide the following:

- Alertness to possible clinical signs of paediatric HIV infection, with appropriate diagnostic testing/referral.
- Protocol for seeking advice from a specialist HIV paediatric or family serviceⁱ regarding the immediate management/transfer of children presenting with serious symptomatic HIV disease.
- Protocol for referring HIV positive children, and infants of infected mothers, to a specialist HIV paediatric or family service and to appropriate voluntary or community support.
- Protocol for managing potential occupational exposure incidents and obtaining advice and PEP by arrangement with other suitable local services.
- Sensitive and effective infection control protocols designed to protect the welfare of patients and staff while avoiding stigma.

4.6 GUM, sexual health clinics

There may be some GUM or sexual health clinics which do not provide ongoing care for people with diagnosed HIV infection (ie do not operate as out-patient, in-patient or comprehensive HIV units).

However, the open access nature of these clinics provides a key entry point for patients to HIV services, and all such clinics should offer the following minimum HIV-related provision:

- HIV testing service on a fully open access basis.
- Advice on HIV prevention and safer sex on a fully open access basis.
- Advice and support on partner notification.
- Protocol for referring HIV positive patients to out-patient, in-patient or comprehensive HIV unit for on-going care, and to community or voluntary sector services able to provide support.
- The development of shared care for drug users in GUM and Sexual Health settings where appropriate.
- Protocol for managing needle-stick and other potential occupational exposures to HIV and providing advice and PEP where necessary.
- Audit of service uptake and where necessary implementation of measures to increase accessibility and cultural and linguistic appropriateness (eg health advocates) for groups who may be under-served.

ⁱ See note i on page 26.

- Protocol for managing requests for PEP following potential non-occupational exposures.
- Sensitive and effective infection control protocols designed to protect the welfare of patients and staff while avoiding stigma.

4.7 Drugs services

Drugs services also act as a key entry point for patients to HIV services¹³. In terms of HIV provision, drugs services should provide:

- Advice and referral to HIV testing.
- Advice on HIV prevention, safer sex and safer drug use.
- Advice where appropriate, on the safe use and disposal of injecting equipment and provision of, or referral to, a needle exchange.
- Protocol for referring HIV positive patients to rehabilitation and/or other appropriate services to assist with drug use.
- Protocol for referring HIV positive patients to out-patient, in-patient or comprehensive HIV unit for on-going care, and to community or voluntary sector services able to provide support.
- The development of shared care for drug users in GUM and Sexual Health settings where appropriate.
- Protocol for managing needle-stick and other potential occupational exposures to HIV and providing advice on PEP where necessary.
- Audit of service uptake and where necessary implementation of measures to increase accessibility and cultural and linguistic appropriateness (eg health advocates) for groups who may be under-served.
- Protocol for managing requests for PEP following potential non-occupational exposures.
- Sensitive and effective infection control protocols designed to protect the welfare of patients and staff while avoiding stigma.

4.8 Occupational health departments

Occupational health departments should have the following arrangements in place covering all NHS services within their remit:

- Protocols for managing potential occupational exposures to HIV, providing advice and ensuring provision of PEP where necessary.
- Protocols for managing HIV-infected staff.
- Liaison with out-patient, in-patient or comprehensive HIV unit.

4.9 Roles within the HIV care network

This section of the report describes the roles of different providers within the HIV care network. Section 5 describes the standards which these providers should meet.

The structure of HIV care networks will vary. The simplest arrangement is a grouping of out-patient HIV units around one comprehensive HIV unit which provides both clinical leadership and in-patient care. However, in some networks there may be more than one provider of in-patient care, in which case it is especially important for clinical leadership arrangements to be clearly understood. An example would be where one comprehensive HIV unit provides leadership for the entire network, while one or more in-patient units may have some role in leading a more local "mini-network". Networks with more than one comprehensive HIV unit will only be effective if these units work together closely to ensure coherent leadership. In all cases, in line with the principle of subsidiarity (section 3.5 above) the aim of clinical leadership should be to support local providers within the network to offer as wide a range of services as can be achieved within limits of acceptable risk, rather than to centralise care unnecessarily.

4.9.1 Out-patient HIV units

Out-patient HIV units should provide all the services listed in paragraph 4.6 above, plus the following:

- Out-patient care for people with HIV in accordance with the standards in section 5.1 below.
- Taking part in network arrangements including:
 - Seeking advice and/or referring patients appropriately in accordance with network protocols.
 - Multidisciplinary and single disciplinary teamwork whereby professionals from the unit work with colleagues across the network in areas such as:
 - professional education
 - protocol and guideline development
 - multi-centre clinical audit.

In some circumstances, local protocols may determine that some in-patient services for people with HIV can be provided through selected out-patient HIV units, eg via dedicated GUM/ID beds or agreements with other suitable consultant firms.

4.9.2 In-patient HIV units

These units should provide all the services listed in paragraph 4.6 above, plus the following:

- A wide range of in-patient and day care for people with HIV-related disease in accordance with the standards set out in section 5.2 below.
- Out-patient care for their local population.
- Out-patient care for other patients who do not wish to attend a local centre or for whom local care may be inappropriate, eg those who have been attending the in-patient unit over a long period of time, those who work in health care or have other particular requirements for anonymity, and others with special needs.
- Some more specialised aspects of out-patient care for patients from other units within the network, as determined by local protocols.

Standards: Service organisat

- Taking part in network arrangements including:

5 Standards for specific services for people with HIV

Referring patients appropriately in accordance with network protocols.

Multidisciplinary and single disciplinary teamwork whereby professionals from the unit work with colleagues across the network in areas such as:

professional education

protocol and guideline development

multi-centre clinical audit.

- In some cases, a degree of clinical leadership for parts of the network, eg provision of advice to colleagues at or shared audit with nearby out-patient units.

4.9.3 Comprehensive HIV units

These units should provide a fully comprehensive range of in-patient, out-patient and day care to HIV patients on a similar basis to in-patient HIV units, but in addition will have a central role in clinical leadership including:

- Coordinating and leading multidisciplinary teamwork across the network, including professional education, protocol and guideline development, multi-centre clinical audit, and providing a focal point for advice for the entire network and other NHS providers within the area it covers.
- Working with units in other networks to develop inter-network liaison arrangements, eg via BHIVA and other relevant organisations.
- Leading and directing clinical and/or basic research and professional education.

The following standards are proposed as the baseline/minimum level of provision. In some cases, developmental standards have also been identified and are listed in footnotes. It should not automatically be assumed that these developmental standards will in future become part of baseline provision; whether this happens may depend both on local circumstances and on evidence of effectiveness as this emerges.

A fundamental standard for all areas of planned provision for people with HIV is that services should be delivered in a non-discriminatory and culturally appropriate manner for the groups particularly affected by the virus, including gay men, drug users and ethnic minorities. This needs to be taken in account not only within NHS provision, but also in terms of NHS arrangements for referring patients to generic or HIV-specific external service providers.

5.1 Out-patient care

5.1.1 Expertise, roles and functions

In addition to appropriate training and experience, consultants providing out-patient HIV services should take full part in professional development activities through the wider network of providers.

Their involvement in HIV-related work should be sufficient to enable them to keep abreast of this rapidly developing area of medicine, eg the equivalent of one busy clinic per week. An individual consultant's HIV-related work may be spread over more than one providerⁱ eg via split post or satellite clinic arrangements.

Multidisciplinary support should be provided by appropriately trained "named professionals" from the following professions:

- pharmacist, whose roles include adherence support and providing information to patients and other health professionals in addition to prescription monitoring and drug procurement
- clinical psychologist or other mental health professional
- dietitian
- nurse(s)
- professionally trained health advisor
- social worker.

ⁱ Developmental standard: As networks evolve, it may be desirable to increase the proportion of consultants providing HIV care whose work includes sessions at an in-patient or comprehensive HIV unit.

As well as providing direct patient care, each of the professionals within the out-patient unit HIV team should take part in appropriate network activities, eg multi-disciplinary and relevant single-discipline networking, protocol development, educational and audit activities. Training in cultural issues in healthcare relating to HIV may be of value for staff caring for African and other ethnic minority people, and may involve liaison outside the local network in areas where there are few such patients. In areas with substantial African populations, consideration could be given to encouraging staff recruitmentⁱ from this group to facilitate culturally and linguistically appropriate care, although for reasons of confidentiality some patients may prefer to see staff from outside their own community. Effective liaison is particularly important in view of the valuable role of voluntary and community organisations in relation to this group of patients. Advocacy and interpreting services will also play a key role in increasing the accessibility of HIV care.

Some haemophilia centres are likely to act as out-patient HIV units in respect of this group of patients, in which case they should meet the same standards as other such units. However, some people with haemophilia and HIV may use other out-patient HIV units (eg GUM clinics) for their HIV care. Out-patient unit HIV teams should liaise closely with haemophilia specialists in respect of these patients.

5.1.2 Facilities

With improvements in treatment, especially HAART, HIV is increasingly managed within an out-patient setting, although it is uncertain how long this trend will continue. People with HIV can expect to attend regular out-patient appointments over very long periods (several years), at times when they will usually be in good health. It is therefore important that out-patient services should be organised with the patient's convenience in mind, especially as stigma associated with HIV/AIDS can make it difficult for people to request time off work for lengthy clinic attendanceⁱⁱ. Out-patient services at out-patient, in-patient and comprehensive HIV units should meet the following standards:

- clinics for HIV care held at times when all the relevant professionals and services are available
- location within an acute hospital out-patient or GUM setting which is suited to the main population groups served, eg if a high proportion of HIV patients are gay men a shared waiting area with predominantly elderly people and/or children might contribute towards discriminatory attitudes
- consulting rooms which provide confidentiality
- availability of counselling and health advice
- facilities for adequate physical examination, including neurological and eye assessments

ⁱ Including use of the Race Relations Act where appropriate.

ⁱⁱ Developmental standard: Provision of evening clinic services should also be considered. Evening counselling sessions are particularly valuable in view of some patients' frequency of attendance.

Out-patient services

- facilities for administering aerosolised medications in a separate well-ventilated room suitable enclosing device in accordance with the recommendations of the Interdepartmental Working Group on Tuberculosis¹⁴
- laboratory support which can deliver CD4 and viral load testing and other pathology tests with rapid turn-around times, and which meets all relevant laboratory standards such as participating in accredited quality assurance programmesⁱ.
- effective management to streamline clinic arrangements so that patients do not unnecessarily have to attend different sites or to wait repeatedly for contact with different elements of the service (eg doctor, phlebotomist, pharmacy, health advisor/counsellor/adherence support)
- ready access to GUM and drug dependency services
- a wide range of information for patients in a variety of formats, with attention to cultural and linguistic appropriateness for the different population groups affected by HIV and served by the unit. This should include information on:
 - service organisation and network arrangements (see section 5.4 below)
 - HIV-related treatments and adherence support
 - HIV prevention
 - how to access voluntary and supporting services, eg welfare advice
 - how to raise any concerns about the service provided, both orally and informally "on the spot" and through formal complaint mechanisms. There should be no discrimination against patients who raise concerns or complaints.
- liaison with and willingness to respond to issues raised by community and service user organisations.

The following information systems should be in placeⁱⁱ:

ⁱ Developmental standard: Current clinical guidelines do not require access to ultrasensitive viral load assays and/or tests for viral resistance, but these may become a minimum/baseline standard within the foreseeable future.

ⁱⁱ Developmental standards: As networks evolve it would be valuable to introduce computer systems which allow confidential record sharing between out-patient, in-patient and comprehensive HIV units providing care to individual patients. Internet access, eg via the BHIVA/AIDSMap project, could be introduced in a wider range of units. Information technology may become an increasingly valuable tool for communication within networks, eg allowing both staff and patients to access advice

- computer systems for patient-record administration which are compatible and able to interface with the main hospital system, but isolated from it either by effective firewalls or standalone design
- recording of contract minimum data set items together with other specialist information of relevance to HIV care and/or clinical/epidemiological research, including disease category, combination therapy, exposure category, GP shared care
- the ability to output data directly in suitable formats for the Survey of Prevalent HIV Infection and Disease (SOPHID) and AIDS Control Act reports, while recognising that these requirements may change.

5.1.3 HIV therapy and long term care

- full access to current standard antiretroviral therapy must be available; particular attention may be necessary to ensure equal access for groups such as women and drug users
- all prescribing and monitoring should be in line with agreed (eg BHIVA) guidelines and local protocols agreed across the network
- within clinical guidelines, the decision to initiate antiretroviral therapy should be taken by the patient, in consultation with their physician
- the decision of some patients not to take antiretroviral therapy should be treated with respect and these patients should continue to have access to all other services
- adherence support and advice tailored to individual patients' needs; provision should include¹⁵:

from in-patient and comprehensive HIV units as well as general treatment information. Expert systems for clinical management covering topics such as drug interactions and treatment of specific HIV-related conditions might also be useful, but it would be inappropriate to develop such systems separately within each network; rather this might be an area for national or inter-network collaboration.

initial advice before and after starting or changing treatmentⁱ

support on maintenance including a 24 hour telephone advice service for patients (which may be provided from an in-patient or comprehensive HIV unit)

information about community and voluntary sector treatment information and adherence support services including clinical nurse specialist or primary care-based services if available locally

- guidelines and protocols should be updated regularly
- clinicians must offer palliative care designed to relieve pain and distressing symptoms at every stage of disease progression, in line with national generic palliative care guidelines
- access to psychiatry and mental health services should be available
- patients should have access to information about current clinical trials. They should be enabled to participate in trials, eg via referral to a comprehensive HIV unit. Access to current standard treatments or investigations should never be dependent on a patient's willingness to take part in a trial.

5.1.4 Unplanned care

People with HIV require prompt ready access to medical advice eg if symptoms develop between scheduled out-patient appointments. All patients need information on how to seek care appropriately in these circumstances, in accordance with local protocols. Possible arrangements include:

- GP attendance, with subsequent referral if appropriate. To provide this service, GPs must be informed of the patient's HIV status and of local network protocols. An alternative arrangement must be in place for those individuals who have refused consent to GP involvement.
- "S.O.S walk-in" access at the patient's usual provider.
- attendance or telephone advice from an in-patient or comprehensive HIV unit.

5.1.5 Injecting behaviour, sexual and reproductive health

All units providing HIV care should recognise their own role, and that of people living with the virus, in HIV prevention and health promotion. Out-patient HIV units should ensure the following services are available, whether or not the unit itself is based within a GUM setting:

- regular HIV prevention and health promotion interventions, delivered in a sensitive and culturally appropriate manner, including:

ⁱ Developmental standard: Provision of AIDS such as pill-boxes, beepers, diaries, information sheets may become a standard if evidence of effectiveness becomes available.

In-patient services

safer sex advice and support
safer injecting advice and support
access to condoms
needle and syringe exchange
close liaison with and access to drug treatment services
hepatitis B & C testing and hepatitis B vaccination
STI screening and treatment
psychosexual services
information resources.

- advice and support regarding partner notification, including provision for health professionals rather than patients to notify partners in appropriate cases
- cervical screening and colposcopy for HIV positive women
- advice for HIV positive women and men who may be contemplating parenthood, including on minimising risk of HIV transmission at conception for serodiscordant couples
- protocol for referring HIV positive women who are pregnant to specialist obstetric care and HIV care
- contraceptive advice for HIV positive women and men.

5.2 In-patient care

HIV-related in-patient care should ordinarily be provided in in-patient or comprehensive HIV units. Local flexibility may allow some exceptions to this, but in all cases the following minimum standards must be met:

- admission under a consultant-led specialty firm with an interest and expertise in the clinical management of HIV infection
- medical and nursing staff who are comfortable in dealing with patients whose care raises complex and emotive issues and who display a non-judgemental and culturally sensitive approach in relation to sexuality, ethnicity and drug use
- treatment in accordance with national and local guidelines and protocols
- 24 hour access to specialist advice on the complications of HIV disease from an in-patient or comprehensive HIV unit.

5.2.1 In-patient HIV units

In-patient HIV units should meet the standards applicable to out-patient HIV units as well as the following additional ones:

5.2.2 Expertise, roles and functions

In-patient services

Within the in-patient HIV unit, care should be led by a dedicated team, with effective multi-disciplinary working. The team should include:

- medical staff comprising:
 - at least one consultant with training and substantial experience and involvement in HIV/AIDS working in conjunction with other (eg general medical) consultants who share responsibility for such patients
 - sufficient staff in training and/or non-consultant grades whose work includes a remit for HIV to provide full 24-hour cover. Doctors in training grades must work under appropriate supervision at all times.
- sufficient staffing by nurses with appropriate training and experience in relation to HIV and AIDS
- multidisciplinary support involving the following appropriately trained named professionals:
 - pharmacist(s)
 - clinical psychologist(s) and other mental health workers
 - dietician(s)
 - counsellor/health advisor(s)
 - physiotherapist(s)
 - mental health nurse(s)
 - nurse(s)
 - social worker(s)
- manager(s) whose work includes a specific remit for the HIV services.

5.2.3 Facilities

The facilities at the in-patient HIV unit should meet the following specifications:

- designated beds for HIV and related specialties, located in an appropriate clinical area such as a GUM/ID/medical specialty ward
- some single room accommodationⁱ
- ready access to negative pressure facilities which are appropriately sited in line with the recommendations of the Interdepartmental Working Group on Tuberculosis¹³
- ready access to intensive care unit
- structures and facilities to prevent nosocomial transmission of infections.

5.2.4 In-patient unit links with related clinical speciality services

There must be established professional links and access to the following related specialties for patients with HIV, not necessarily on-site but readily and quickly available (for some specialties this

ⁱ Developmental standard: Family provision could also be considered to enable children to remain with a parent when the latter is receiving in-patient care.

In-patient services

may be via liaison with the comprehensive HIV unit):

- radiology including MRI and CT scansⁱ
- oncology via a cancer centre, including radiotherapy
- ophthalmology
- gastroenterology
- respiratory medicine
- psychiatry and other mental health professionals
- neurology
- intensive care
- anaesthesia
- dermatology
- palliative medicine
- rheumatology
- surgery
- medical microbiology/infection control
- immunology
- haematology
- hepatology
- otorhinolaryngology
- histopathology
- ID/Tropical Medicine.

For each of the above specialties there should be at least one consultant firm with a responsibility for HIV.

The HIV team should also liaise closely with haemophilia specialists as regards this group of patients, in whom the management of HIV disease is complicated by the inherited bleeding disorder. Among the specialties listed above, access to hepatology and ID is especially relevant for haemophilia and other HIV patients who are co-infected with hepatitis C.

Links are also needed with a dental hospital or oral surgery specialist team, whose functions should include:

ⁱ Developmental standard: It is desirable for these services to be on-site if at all possible.

In-patient services

- networking and education for community dentistry to enable patients with HIV to access dental services and ensure that community dentists can recognise and refer appropriately for suspected HIV-related oral problems
- provision of a "safety net" for patients unable to access community dental services
- provision of specialised dentistry for complex dental problems directly related to HIV.

Access to residential and non-residential palliative and respite care should be available, which may be provided through generic or dedicated HIV services. Further work may be needed to develop standards covering staffing levels, training and experience for providers of HIV-related palliative and terminal care, but as a minimum these services should meet generic palliative care guidelines and should be delivered in a sensitive and non-judgemental manner for people with HIV.

In addition, there should be access to the following highly specialised services which, depending on local epidemiology, may be shared between more than one network:

- HIV-specialist paediatricsⁱ

ⁱ This document does not seek to provide detailed standards for paediatric HIV care, which is a highly specialised area. An initiative will be under way shortly in relation to standards for paediatric HIV services within the London area. Ideally paediatric HIV care is best provided through family services but this is unlikely to be feasible in areas where there are few infected children. Except in high prevalence areas, access to a sufficient level of specialist paediatric HIV expertise may necessitate centralisation of care, while recognising that this means patients potentially having to travel considerable distances, as is the case for children with other rare but complex conditions. Family and paediatric HIV services need to communicate well with community, primary care and voluntary services wherever the infected child lives, to enable effective support.

Clinical leadership and comprehensive HIV units

- obstetric services for HIV positive womenⁱ, which should have protocols for liaison with HIV-specialist paediatric services so that women can discuss care arrangements prior to their baby's birth
- services for people with neuropsychiatric problems due to HIV, including brain impairment.

5.2.5 Day care

Usage of day care by people with HIV is declining as a result of treatment advances but a residual level of need is likely to continue indefinitely. As a minimum standard, day care should be provided in settings where staff are sufficiently familiar and comfortable with HIV to ensure both technically competent care and that patients are not exposed to, for example, unnecessarily obtrusive infection control precautions. In practice, however, in most cases it will be appropriate for day care (especially investigational procedures) to be provided via in-patient or comprehensive HIV units. The following provision should be available:

- beds for investigation, transfusion, chemotherapy, IV therapy and other interventions requiring temporary hospitalisation.

5.3 Clinical leadership and comprehensive HIV units

Comprehensive HIV units should provide a fully comprehensive range of HIV hospital services on broadly similar lines to in-patient units, and should meet all the standards applicable to both out-patient and in-patient HIV units. The main distinction between in-patient and comprehensive units lies in arrangements for coordinating professional development and providing clinical leadership to the network. In-patient units may have some role in clinical leadership, especially for the most nearby out-patient units, but the comprehensive unit will have primary responsibility for providing clinical leadership and supporting team-building across the entire network. Having said this, comprehensive units will usually be larger and more intensively staffed than in-patient units within the same network, with on-site access to a larger number of related specialties.

Within the comprehensive HIV unit, care should be led by a dedicated team, with integrated management to ensure effective multi-disciplinary working. The team should include:

- medical staff comprising:

ⁱ As for paediatric services, there are particular difficulties in providing specialist HIV obstetric services in areas where infected pregnant women are few and scattered, and further work is needed to develop standards for these services.

a team of consultants appropriately trained in HIV/AIDS, with substantial experience of managing such patients

SpRs in training and/or non-consultant grades as appropriate

at least five medical SHOs within the trust whose job descriptions include a remit for HIV, so as to provide full cover. These staff must work under appropriate supervision at all times.

- sufficient staffing by nurses with appropriate training and experience in relation to HIV and AIDS, including clinical nurse specialists on call
- the following appropriately trained dedicated professionals:
 - pharmacist(s)
 - clinical psychologist(s)
 - dietician(s)
 - counsellor/health advisor(s)
 - physiotherapist(s)
 - mental health nurse(s)
 - nurse(s)
 - social worker(s)
 - director manager(s).

5.3.1 Clinical leadership

The comprehensive HIV unit team should provide clinical leadership for the network as a whole including:

- 24-hour advice to colleagues at out-patient and in-patient HIV units and to other NHS providers within the area covered by the network
- consultant outreach to other HIV units within the network eg via split posts or satellite clinics
- convening or jointly convening a medical forum in which physicians from all providers within the network should participate. The work of the forum should include:
 - regular linking and educational meetings, for which there should be recognised time within consultants' workplans
 - development of agreed network-wide guidelines and protocols which define triggers for referral
 - coordinating joint clinical audit covering all providers within the network
- initiating and supporting arrangements whereby clinical staff at out-patient and in-patient HIV units can participate in research and teaching (eg via honorary clinical lectureships), both to enable their patients to access clinical trials and to cement relationships within the network
- convening and leading single-discipline professional development for the named and/or

Communication and interfaces

dedicated non-medical staff involved in HIV care from all units across the network, including running study days and clinical updates as appropriate

- promoting lifelong learning for all professionals within the multi-disciplinary network team
- linking with other networks, including through professional organisations, for activities such as developing policies, guidelines, educational approaches and outcome measures.

5.3.2 Research

Comprehensive HIV units should be significantly involved in leading and conducting clinical and/or basic research, including taking part in multi-centre studies involving collaboration with other networks and/or internationally. Part of this role is to communicate regularly with all other units within the network about current trials and to work with them so that patients attending other units can participate in trials on an equitable basis without needing to transfer their ordinary care to the comprehensive unit.

5.4 Communication and interfaces

There should be systems in place to facilitate smooth and timely referrals across organisational boundaries both between out-patient, in-patient and comprehensive HIV units and with the community and external providers, including social care and voluntary services. The interface between the Prison Service and the NHS should be considered, so that planned referrals can take place, to ensure continuity of treatment. This requires genuine two-way communication for which both sides should take responsibility. In addition to coordination of the care of individual patients, professional development activities should be designed to facilitate understanding of the roles of different agencies.

The following arrangements should be planned on a network-wide basis to ensure consistency, although the detail may vary for different units as some external agencies may not cover the full extent of the network:

- effective communication between all the units within the HIV care network
- agreed systems for communicating regularly with primary care, which guarantee appropriate confidentiality without compromising effective delivery of care
- ensuring that the value of GP involvement or shared care is discussed with recently diagnosed patients, that, where necessary, advice is given on changing GP and that GP contact details are recorded and re-checked regularly (eg annually)
- providing information to patients about the extent of the network and how it operates, for example so that patients understand from the start that if they may be referred to unit other than their usual source of outpatient care if they become ill or require a higher degree of specialist input. Given the sensitivity of confidentiality in relation to HIV/AIDS, it is particularly important that patients understand arrangements for information sharing within networks.

- ensuring that if consent to GP involvement has been withheld, this decision is reviewed with the patient annually and following any substantial change in clinical status.
- ensuring information on how to access rapid advice about HIV-related problems is made available to community and primary health care services
- effective mechanisms for communicating with related specialties
- close links to drug misuse services, ensuring that needle exchange, methadone programmes and alcohol/drugs detox are available to HIV positive drug users
- referral procedures to appropriate advocacy, counselling, peer support and patient education services, most of which are likely to be located in the voluntary sector
- ensuring information about NHS services is made available to community and service user organisationsⁱ
- ensuring appropriate information about services available from community and service user organisations is made available to patients within the NHS setting
- mechanisms for forging links with the community, including regular liaison arrangements between named contact(s), eg in-patient or comprehensive HIV unit manager(s), and service user fora representing the main communities served by the network.

In the case of in-patient and comprehensive HIV units, which may draw patients from outside their own area, it is particularly important to have effective mechanisms for liaising with local authorities, including social services and housing, community care and voluntary services throughout the area covered by the network (or part of the network covered by an in-patient HIV unit). However, to avoid confusion and duplication, HIV-specific liaison needs to be integrated with more generic community care coordination and discharge planning arrangements which may already exist for other groups of patients. Clearly this is a two-way process which requires cooperation from both hospital

ⁱ Developmental standards: Activities such as open days should also be considered to encourage awareness and confidence in NHS service arrangements among these organisations and their service users. Closer organisational links with voluntary providers should also be developed, such as "one-stop shops" offering voluntary services (eg welfare advice, adherence support, prevention and treatment information) within or via NHS HIV units, while taking account of the needs of different patient communities. The convenience this provides is particularly desirable in view of the changing spectrum of HIV disease, as more people are well and in work.

6 References and interfaces

and non-hospital services, eg for social service departments to provide prompt assessments for people with HIV.

Community-based clinical nurse specialists have a well-developed role in the care of people living with HIV in some areas. Where this is the case, patients should be offered referral to the CNS. Patients who decline referral should be given information about how to contact the CNS directly if they wish to do so at a later date. These nurses should be closely linked with the network of hospital-based services, to enable effective coordination of patient care and to support their own professional development.

Annex 2: Examples for local protocols

AGM:	Annual General Meeting
AGUM:	Association for Genito-Urinary Medicine
AIDS:	Acquired immune deficiency syndrome
BHIVA:	British HIV Association
CD4:	Lymphocytes bearing the CD4 marker
CNS:	Clinical nurse specialist
CT:	Computerised tomography
DGH:	District general hospital
GP:	General practitioner
GUM:	Genito-urinary medicine
HA:	Health authority
HAART:	Highly active (combination) antiretroviral therapy
HIV:	Human immunodeficiency virus
ID:	Infectious diseases (as a medical specialty)
IV:	Intravenous
MRI:	Magnetic resonance imaging
NHS:	National Health Service
PACT:	Association of NHS Providers of AIDS Care and Treatment
PEP:	Post-exposure prophylaxis
R&D:	Research and development
SHO:	Senior house officer
SpR:	Specialist registrar
STI:	Sexually transmitted infection
VL:	Viral load

Implementation of standards for HIV care should be via local development of network structures and protocols which conform with the principles set out in this report. Protocols are particularly important in defining the working relationship between different elements within a network, such

Annexes: page 33

as triggers for seeking advice or referring patients from an out-patient to an in-patient HIV unit.

Annex 3: Case studies/examples of network arrangements

Protocols differ from clinical guidelines in that they specify the mechanism for making treatment/investigation decisions, not what those decisions might be. While clinical guidelines are obviously valuable, protocols can offer a more robust approach in rapidly developing areas of medicine, as they do not become out of date so quickly.

The following examples are intended to be illustrative, not prescriptive:

An overall protocol might specify the agreed roles, responsibilities and methods of consultation between network participants in common situations, including admission and discharge arrangements.

A protocol might specify the combination therapy of choice for treatment-naive patients, but also mechanisms for seeking advice about the care of patients for whom this combination might be unsuitable.

A protocol might specify that doctors at an out-patient HIV unit should seek advice from a consultant at an in-patient or comprehensive HIV unit before prescribing for a patient whose VL has risen, indicating possible failure of current anti-retroviral therapy.

A protocol might specify which symptoms/conditions can be managed within out-patient HIV units and which should prompt immediate referral for assessment at an in-patient or comprehensive HIV unit.

A protocol might specify the location of in-patient care, which might be provided by a single centre (the comprehensive HIV unit) or shared between the comprehensive unit and in-patient centres, where these are in place.

Network around Sheffield: Each GUM consultant at the Royal Hallamshire hospital takes responsibility for providing care at a neighbouring DGH. All posts are shared, but each provider operates as an autonomous unit. Clinical responsibility is contracted for explicitly. In-patient care is centralised at the Royal Hallamshire. Centralised pharmacy purchasing arrangements achieve drug price reductions for the providers within the network.

North Western region: A regional HIV Physicians Forum meets regularly and agrees common clinical guidelines. The Monsall regional unit at the North Manchester General Hospital negotiates with purchasers on behalf of the network as a whole. Consultants at the Monsall provide satellite clinics at some neighbouring DGHs. Following the appointment of a consultant in Blackpool a "managed re-patriation" process has taken place. Consultants in Manchester have worked with Blackpool patients to develop an incremental shared care arrangement with Blackpool clinicians, so that

Annex 4: List of project participants

patients have been reassured of the quality and acceptability of local services. Explicit categories of patients for whom "re-patriation" would be inappropriate have been excluded from this arrangement.

St Mary's Hospital and Royal Hospitals Trust, London: Both centres operate well-developed network arrangements which include honorary contracts with consultants from outlying services and the provision of educational events.

The report *Developing service networks for care in London*³ gives further examples of network arrangements within the London area.

The BMA Foundation for AIDS and the Centre for Research on Drugs and Health Behaviour would like to thank the following people for their contribution to this project:

Participants in the initial workshop

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Willie Harris (St Mary's Hospital): Association for Genito-urinary Medicine
Brian Gazzard (Chelsea & Westminster Hospital): BHIVA
George Kinghorn: Royal Hallamshire Hospital, Sheffield
Christine Lee (Royal Free Hospital): UK Haemophilia Centre Directors HIV/AIDS Working Group
Joshua Odongo: African HIV Steering Group
Steve Jamieson: RCN HIV Nursing Forum
Tony Pinching (St Bartholomew's Hospital): PACT
Anton Pozniak: King's College Hospital
Rosie Weston (St Mary's Hospital), Claire Richardson (Chelsea & Westminster Hospital): AIDS Pharmacists Group
Edmond Wilkins: North Manchester General Hospital

In addition, articles on the project appeared or are planned in the following publications:

Vanguard

Positive Nation

Impact (National AIDS Trust)

AIDS Treatment Update

Discussions have taken place at meetings of the following groups:

African Steering Group

Pan-London Providers Consortium Lobby Group

PACT Steering Committee and AGM

HIV (England) Commissioners Group

Inner London HIV Health Commissioners Group

Written responses to consultation

The following organisations submitted written responses to the consultation draft:

AIDSline Exeter

Association for Genito-Urinary Medicine

Birmingham City Council Social Services Department

British Federation against Sexually Transmitted Diseases

British Infection Society

British Medical Association Committee for Public Health Medicine & Community Health

British Medical Association General Practitioners Committee

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British Medical Association Scottish Office

Bromley Health Authority
Chief Nursing Officer and Director of Quality for NHS, Department of Health
Devon HIV & AIDS Association
East Surrey Health Authority
East Sussex, Brighton and Hove Health Authority
Faculty of Public Health Medicine
Gloucestershire Health Authority
Health Quality Service
Inner London HIV Health Commissioners Group
Joint Committee on Higher Medical Training
Lambeth, Southwark and Lewisham Health Authority
London Lighthouse
Manchester Health Authority
Medical Society for the Study of Venereal Diseases
National AIDS Trust
Network of Self Help HIV and AIDS Groups
Newcastle and North Tyneside Health Authority
NHS Executive South and West
Northern Local Authority HIV Co-ordinators' Forum
Patients Association
Royal College of General Practitioners
Royal College of Physicians
Royal College of Surgeons of England
Terrence Higgins Trust
UK AIDS Pharmacists Group
UK Haemophilia Society
Wessex HIV Network Group/Wessex GUM Clinical Group
West Hertfordshire Health Authority
West Kent Health Authority
York Health

Further written responses were received from clinicians based at the following organisations:

Bethlehem and Maudsley NHS Trust
Blackpool Victoria Acute Hospital NHS Trust
Brighton Healthcare Trust

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Camden and Islington Community Health Services NHS Trust

Central Sheffield Hospitals NHS Trust
Doncaster Royal and Montagu Hospital NHS Trust
Ealing Hospital NHS Trust
Eastbourne and County Healthcare NHS Trust
Guy's and St Thomas's Hospital Trust
Harrogate Healthcare NHS Trust
Homerton Hospital NHS Trust
King's Healthcare NHS Trust
Medical Research Council HIV Clinical Trials Centre, University College London Medical School
MidKent Healthcare NHS Trust
Mildmay UK
Mount Vernon and Watford Hospitals NHS Trust
North Manchester Healthcare NHS Trust
Peterborough Hospitals NHS Trust
Pinderfields and Pontefract Hospitals NHS Trust
Ravensbourne NHS Trust
Royal Devon & Exeter Healthcare Trust
Royal Free Hampstead NHS Trust
Royal Hospitals NHS Trust (Belfast)
Royal Infirmary of Edinburgh NHS Trust
St George's Healthcare NHS Trust
West Suffolk Hospitals NHS Trust

Participants in the second workshop

The following people took part in the second project workshop held on 16 November 1998.

Dr F Ahmed, Bromley Health Authority
Dr Jonathan Ainsworth, North Middlesex Hospital
Gary Alessio, Pan London HIV/AIDS Providers Consortium
Peter Andrew, Newcastle and North Tyneside Health Authority
Dr Stephen Ash, The Pasteur Suite Infection and Immunity Unit, Ealing Hospital
Dr T Balachandran, Luton & Dunstable Hospital NHS Trust
Anna Bamford, Royal College of Nursing HIV National Nursing Forum
Sarah Barber, Bromley Hospitals NHS Trust
Mike Bunting, Gloucestershire Royal NHS Trust, County HIV/AIDS Counselling & Support Service
David Cooper, East Surrey Health Authority

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Dr Andrew Dunford, QMW College/Royal College of General Practitioners

Dr Barry Evans, Communicable Diseases Surveillance Centre/Public Health Laboratory Service
Amanda Field, St Mary's Hospital
Dr Martin Fisher, Royal Sussex County Hospital
Neil Fraser, SUPWA Group, Pan London HIV/AIDS Providers Consortium
Dr Patrick French, Mortimer Market Centre
Professor Brian Gazzard, BHIVA/Chelsea and Westminster Hospital
Sister Green, Ealing Hospital
Judith Greenwood, Birmingham Health Authority
Ceri Hutton, Health Quality Service
Will Huxter, Inner London HIV Health Commissioners Group/Lambeth, Southwark and Lewisham HA
Suzanna Jauhar, Lambeth, Southwark and Lewisham Health Authority
Dr Margaret Johnson, BHIVA/Royal Free Hospital
Linda Johnson-Laird, Communicable Disease Branch, Department of Health
Dr G R Kinghorn, Royal Hallamshire Hospital
Ian Kramer, UK Coalition of People Living with HIV & AIDS Ltd
Dr Andrew M L Lever, Addenbrooke's Hospital
Dr R D Maw, Royal Victoria Hospital, Belfast
Paul McCrory, Network of Self-Help HIV and AIDS Groups
Dr Jeanette Meadway, Mildmay UK
Jane Mezzone, East Sussex, Brighton & Hove Health Authority
Riva Miller, Royal Free Hospital
Dr Mayura Nathan, Homerton Hospital NHS Trust
Dr Adrian Palfreeman, Peterborough District Hospital
Dr Barry Peters, MSSVD/St Thomas's Hospital
David Regan, Manchester Health Authority
Geraldine Reilly, Middlesex/UCLMS Prison Medical Education
Dr Chris Taylor, King's Healthcare NHS Trust
Dr Nick Theobald, Chelsea and Westminster Hospital/Royal College of General Practitioners
Tricia Urquhart, Southampton Community Health Services Trust
Saul Walker, National AIDS Trust
Dr Jan Welch, King's Healthcare NHS Trust
Carole Wells, Pharmacy Department, St George's Hospital
Rosie Weston, UK AIDS Pharmacists Group
Dr Ian Williams, Camden and Islington Community Health Services NHS Trust
Dr Kevin Woodcock, Winchester and Eastleigh Healthcare NHS Trust
Zoe Wright, St Bartholomew's Hospital/PACT

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Tera Younger, South Thames NHS Executive Region

Facilitators: Jane Carrier (Centre for Research on Drugs and Health Behaviour), Hilary Curtis (BMA Foundation for AIDS), Sheila Marsh, Tricia Wass.

1. Funding from Bristol-Myers Squibb Pharmaceuticals has been in the form of unrestricted support for the BMA Foundation for AIDS, and the company has had no input into this document.
2. Luger L, Carrier J et al. Developing the agenda- HIV services in the late '90s and beyond. London: NHSE North Thames, 1997.
3. Carrier J, Luger L, French K, Wass T. Developing service networks for HIV care in London. London: The Centre for Research on Drugs and Health Behaviour, 1998.
4. A first class service: quality in the new NHS. London: Department of Health, 1998.
5. Clinical governance is defined in *A first class service: quality in the new NHS* as "a framework through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish". The clinical governance framework includes quality improvement activity (eg clinical audit, evidence-based practice, monitoring of clinical care), policies for managing risk including procedures to identify and tackle poor performance, and clear lines of responsibility and accountability for the overall quality of clinical care including regular reporting to Trust Boards.
6. Letter dated 13 August 1998 from David Walden, Stocktake Group Chairman, Department of Health, to HIV/AIDS Stocktake Group Members.
7. Maxwell R J. Quality assessment in health. *Br Med J* 1984; **288**: 1470-1.
8. Rogers P A, Whitmore-Overton S E, Evans B G, Allardice GM, Noone A. Survival of adults with AIDS in the United Kingdom. *CDR Review (Communicable Disease Report)* 1997; **7**: R93-100.
9. Stone V E, Seage G R, Hertz T, Epstein A M. The relation between hospital experience and mortality for patients with AIDS. *JAMA* 1992; **268**: 2655-61.
10. A policy framework for commissioning cancer services. A report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales. Guidance for Purchasers and Providers of Cancer Services. April 1995.
11. Paediatric intensive care "A framework for the future". Report from the National Coordinating Group on Paediatric Intensive Care to the Chief Executive of the NHS Executive. Department of Health Report 11003 HCD5KIP, July 1997.
12. Reducing mother to child transmission of HIV infection in the United Kingdom. Recommendations of an Intercollegiate Working Party for Enhancing Voluntary Confidential HIV Testing in Pregnancy. Royal College of Paediatrics and Child Health, April 1998.
13. For further advice in this area see the updated report *Drug Misuse and Dependence - Guidelines on Clinical Management* (1999) from the Department of Health.
14. The Interdepartmental Working Group on Tuberculosis. UK guidance on the prevention and control of transmission of 1. HIV-related tuberculosis 2. Drug-resistant, including multiple drug-resistant tuberculosis. London: Department of Health, 1998.
15. The 1998 Inner London HIV Health Commissioners Group report *Establishing a pan-London framework for HIV treatment compliance* provides helpful guidance for adherence services especially in higher prevalence areas.