

Networking for quality in HIV treatment and care

Report of findings from a project
to map and facilitate the
development of service networks
in four parts of England.

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MEDICAL FOUNDATION FOR
AIDS & SEXUAL HEALTH*

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FOREWORD

Working in service networks can help clinicians and other providers to meet shared standards of care, so that people living with HIV have access to consistent and equitable service quality, regardless of where they live. In 1999-2001, an exercise took place to map the development of networking in HIV services in four parts of England, and to facilitate local discussion on the potential for the further development of networks. This report presents the findings of that exercise, which was managed by the Medical Foundation for AIDS & Sexual Health (MedFASH), then known as the BMA Foundation for AIDS.¹

The findings emerging from the mapping exercise were part of the rationale for a new project taking place in 2002, to develop new standards for NHS HIV services. This project is being managed by MedFASH, which is also undertaking a programme of work to further facilitate the development of HIV service networks.

The new project, funded by the Department of Health, London health authorities, the British HIV Association (BHIVA) and the National Association of NHS Providers of AIDS Care and Treatment (PACT), responds to the government's *National strategy for sexual health and HIV (2001)*. The *strategy* and its implementation action plan state that updated national HIV standards will be developed and that all HIV treatment and care should be provided within networks.

This report presents a series of recommendations arising from the project. It describes the genesis of the mapping and facilitation exercise and the fast-changing policy context within which its findings should be considered, followed by the main findings and a short list of success factors and obstacles to network development which emerge from them.



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RECOMMENDATIONS

Standards

We welcome the commitment in the *The national strategy for sexual health and HIV* to the development of new standards for NHS HIV services and the fact that MedFASH is now managing the implementation of this commitment with the involvement of stakeholders. We recommend the following.

- 1 Standards for NHS HIV services should be regularly reviewed, updated and disseminated and a clear process, with accompanying resources, should be agreed for this.
- 2 Clear quality standards should be developed and regularly updated applicable to the range of areas of HIV clinical treatment and social care where they currently do not exist: eg paediatric HIV, treatment of people with HIV in custodial settings. These should form a coherent structure following agreed principles for standard development. The inclusion of guidelines for treatment of pregnant women and the prevention of mother to child transmission in the BHIVA guidelines (2001) is to be welcomed as part of this process.

Networks

We welcome the fact that *The national strategy for sexual health and HIV* requires the development of managed service networks for HIV. In order to ensure that these networks are effective we recommend the following.

- 3 The use of the term 'networks' should be clarified and a national strategic approach to their uses outlined.
- 4 Health professionals must be well informed about the concepts and implications of networks through professional education. They also need to have the opportunity to discuss fears and anxieties and learn from existing practice. Fear and competition are identified in this report as major barriers to network development.
- 5 Service networks should initially build on existing links and contacts.
- 6 Clear leadership and management must be identified early on in network development.
- 7 There is no single model for network development and it is possible for a variety of models to co-exist as long as there are local consensus and clear lines of accountability for quality standards.
- 8 Resources and technical support must be made available to establish a more effective electronic infrastructure to support networking.
- 9 Mapping exercises and facilitated, participative sessions should be integral to network development with an emphasis on open and regular communication and whole-system events.
- 10 Resources should be identified and made available to support network development. These include financial support for clinical cover, training days, opportunities for information sharing or attendance at educational events about networks, electronic infrastructure and, where appropriate, staff dedicated to network development.

Multi-disciplinary approach

- 11 HIV care should be delivered by a range of professionals who coordinate around user needs. This allows for broad communication at educational events, and patient care tailored to needs around multi-faceted issues such as support for adherence.
- 12 People providing HIV services in a broad range of settings need to be included in a network so as to benefit from advice and support and to share their expertise.
- 13 Multi-disciplinary working should include:
 - 13.1 clinicians with a local lead role in HIV care including those in genitourinary medicine (GUM), infectious diseases (ID), paediatric HIV and other related specialties.
 - 13.2 community-based clinical nurse specialists (CNSs) as well as hospital nurses and accident and emergency staff.
 - 13.3 pharmacists, dieticians, dentists, mental health nurses, midwives, social workers and other related professions.
 - 13.4 primary care teams.
 - 13.5 services working with people with HIV who are treated in specific settings such as haemophiliacs, pregnant women using maternity services, people in prison or detention centres, and drug users.

Input from people living with HIV

- 14 User consultation needs to be improved and linked to evidence-based principles of good practice in consultation, including feedback to service users on responses to their views.
- 15 Consultation mechanisms developed for HIV/AIDS should be integrated into the wider NHS partnership and patient involvement mechanisms.
- 16 The changing needs of people living with HIV must be identified and these must influence the planning of service delivery for people living with HIV.

Commissioning and funding

- 17 When significant changes in commissioning or NHS structure are going to occur, these should be clarified promptly and clearly, including the implications for HIV services, to all those responsible for commissioning and providing HIV healthcare services, in order to avoid long periods of uncertainty.
- 18 HIV commissioning should be undertaken across an area large enough to cover the development of a network. In many cases, this is likely to correspond to the size of a strategic health authority (StHA).
- 19 It is important that commissioning be informed by a combination of HIV specialist knowledge and an understanding of existing local provision.

BACKGROUND

This paper reports on the findings of the project on **Networking and standards for NHS hospital HIV services** (hereafter referred to as the *networking and standards project*) carried out during 1999-2001 by MedFASH, a charity supported by the British Medical Association and previously known as the BMA Foundation for AIDS. The project took place against a background of rapid improvements in the medical treatment available to people living with HIV in the UK, which has resulted in a reduction in inpatient care and a shift towards accessing medication in outpatient settings, as well as a period of major strategic reform in the National Health Service (NHS). Both of these elements were subject to development and further progress during the process of the *networking and standards project* and have had an impact on findings.

The starting point for the project was a concern to ensure that people living with HIV have consistently high standards of treatment and care regardless of where they live or which providers they use. The medical management of HIV is increasingly complex. In many parts of the country, particularly rural areas, HIV is still relatively rare. There is evidence from research in relation to other medical conditions that clinical outcomes are poorer in smaller and isolated units, and some evidence from the UK and USA that this is the case for HIV although most findings pre-date new developments in therapy and should be treated with caution.^{2,3} At the Ninth Retroviruses Conference in Seattle in 2002, it was reported that mortality rates are affected by whether or not a physician is experienced (defined as a physician who had enrolled more than five people into an HIV treatment programme) particularly for those with lower levels of immunity where the difference is quite substantial (2.9% as against 17.6%⁴ at 12 months follow up).

In the mid-1990s projects were initiated in London by the Centre for Research on Drugs and Health Behaviour (CRDHB) and North Thames Health Authority^{5,6} to review access to and quality of HIV acute care in the light of the changes resulting from the development of new combination highly active antiretroviral therapy (HAART). These culminated in recommendations for developing the 'network model' through which smaller and larger centres would work collaboratively to ensure consistently high standards of care. A network of HIV service providers, while retaining local flexibility, would typically be multi-disciplinary and consist of:

- a number of outpatient HIV units, often located in district general hospitals (DGH)
- a smaller number of inpatient HIV units, likely to be located at hospitals with their own investigative and treatment facilities
- one or more comprehensive HIV units providing the full range of HIV treatment services and with the potential to provide overall clinical leadership for the network, including research, education and audit.

A key driver of the development of service networks for HIV was considered to be agreed quality standards. In 1998 *Standards for NHS hospital HIV services*⁷ were developed through a process managed by the CRDHB and MedFASH (then the BMA Foundation for AIDS, which also published the standards). Their development was designed to progress managed service networks.

The *networking and standards project* built on the earlier work described above. It played a central part in the strategic work of MedFASH to develop understanding and progress development of HIV service networks and standards. It had two objectives:

- to assess the current state of development of service networks among providers of hospital care for people with HIV in areas of England outside London through mapping of services;

- and to facilitate local discussions about how such networks might be strengthened and developed further, broadly in line with proposals in the report *Standards for NHS hospital HIV services* (1998).

We wanted to look at configurations of care in areas of England that were not associated with a high prevalence of HIV in order to understand:

- how services were organised
- how people with HIV were accessing them
- whether the *Standards for NHS hospital HIV services* were being implemented in these areas
- and if so, whether they were perceived as applicable in a range of centres with variation in numbers of patients and geographical locations.

We carried out mapping and network facilitation in four parts of England: the South East (Surrey, Sussex and Kent), West & North Yorkshire, the West Midlands and the South West (the latter two each covering a whole NHS Region and the others covering parts of the South East and North East Regions respectively). These were all areas with a relatively low prevalence of HIV, except for Brighton in the South East.

Information from the project is organised under five categories:

- standards
- networking
- multi-disciplinary approach
- input from people living with HIV
- commissioning and funding.

This paper summarises the findings of the project, makes recommendations and identifies the learning which should inform the further development of networks as a means of ensuring quality standards of HIV care throughout the NHS.

NETWORKS AND STANDARDS IN NATIONAL POLICY

The *networking and standards project* took place at a time of significant and fast-moving changes in the NHS, some specific to HIV but others much broader. During the mapping exercise, we encountered anxiety among professionals about the implications of the move to residence-based funding for HIV treatment and care, and a desire to clarify arrangements for specialised commissioning at regional level. But within a year, these concerns were overtaken by bigger changes. HIV budgets were increasingly being mainstreamed and commissioning was moving to primary care trusts (PCTs).

Strategic change in the NHS was causing upheaval and anxiety but also clearly offered opportunities for improving patient care, and these have continued to emerge. A number of major national policy documents have made it clear that quality standards and managed networks are key tools for NHS reform.

The *NHS Plan*⁸ set out a number of the problems besetting the health service as follows:

- a lack of national standards
- demarcations between staff and barriers between services
- lack of incentives and levers to improve performance
- over-centralisation and disempowered patients.

The solutions proposed by the plan were aimed at 'a health service designed around the patient', with national standards for all major conditions, doctors and nurses to work to standard protocols and a 'real say' for patients, through information, choice and advocacy.

The network model was already being developed in a wide spectrum of specialties notably cancer, paediatric care, and TB services in London among others. Networks were presented as a key component of Scottish and Welsh plans for improving the organisation of acute care.^{9,10}

When *Shifting the balance of power within the NHS: securing delivery*¹¹ was published, it was clear that clinical networks were embedded throughout the proposed new organisational structures for the NHS in England. National clinical standards were presented throughout as the solution to ending the 'lottery of care' in the NHS (para 8). NHS trusts would be expected to "...foster and encourage the growth of clinical networks across NHS organisations..." (para 3) while strategic health authorities (StHAs) would manage performance across organisational boundaries and networks (para 30).

*Shifting the balance of power within the NHS: the next steps*¹², published after consultation on *Shifting the balance of power within the NHS: securing delivery*, emphasised the cultural changes needed to reform the NHS, underpinned by structural re-organisation.

- **Primary care trusts** would hold resources to shape and commission services across hospital, community and primary services from the range of possible providers.
- **NHS trusts** would continue to provide services, develop further patient and staff involvement, and engage in creating networks for care with external partners.
- **Strategic health authorities** would develop strategy and performance manage PCTs, NHS trusts and Workforce Development Confederations so as to secure delivery and consistency of approach (para 1.4.1).

The strengthening of relationships across sectors would be enabled through 'the drive to develop networks of care, ...designed around care pathways which may involve both health and social care,' (para 1.4.3). StHAs would '[sit] at the centre of a range of networks that represent a health and social care system, ...and [broker] solutions across those networks' (para 2.2.4).

Two of the 14 main proposals for *The national strategy for sexual health and HIV* in England¹³ relate to networking and standards. These are influenced to some extent by the body of work from MedFASH and CRDHB referred to above.

The *national strategy* states as an aim the development of managed service networks:

“...allowing providers to collaborate and plan services jointly and so provide a more comprehensive service to patients. This is essential for HIV services. It will also strengthen provision in areas like STIs, contraception and psychological and sexual problems.”(para 4.6).

Paragraphs 4.56-4.63 summarise the rationale and proposals for managed networks in HIV services. The importance of partnerships, flexible working and collaborative care are all emphasised. The key statement of the strategy is that:

“All HIV practitioners will be expected to work within a managed service network, which means that all HIV treatment and care should be given within the networks. Networks will decide how partnerships between smaller and larger units will work by clearly indicating roles and responsibilities.” (para 4.60).

Networks will support non-specialist HIV care, the voluntary sector and user groups as well as providing a focus for local training and professional development.

The importance to successful network development of nationally agreed guidelines on treatment and care and locally agreed care pathways is emphasised. Stating that “updated national HIV standards will be developed by 2002”, the strategy offers the earlier work on standards as a template (para 4.62).

The concept of networks emerged from discussions within organisation theory during the 1990s. A paper by the then NHS South East Regional Office¹⁴ reviews the literature on networks and cites a definition of a network as “a set of autonomous organisations that come together to reach the goals that no one can reach separately”.¹⁵ Networks, it has been argued, can respond to ‘inter-related’ or ‘meta problems’ which are beyond the capacity of single organisations and can only be dealt with through inter-organisational collaboration.¹⁶ The literature on network organisation views them as an alternative to vertical integration, with an emphasis on collaboration and trust as opposed to market and competitive behaviour. The recent period when the internal market dominated in NHS development caused, as was pointed out by a number of participants in this project, a breakdown of many natural networks and collaborative working patterns in the healthcare system. Within the debates around future healthcare, particularly with reference to the balance between quality and access, networking is seen as one of the options. An alternative approach might include the physical relocation of services where patients are expected to move to a centralised service or the increased use of information technology (IT) where it is the patient information, which is transferred. Networking, however, provides a model where clinicians work collaboratively across administrative boundaries.

Concepts of ‘networks’ across the NHS are varied and developing. This means there can be confusion among those expected to implement their creation, but it also provides scope for networks to develop in ways appropriate to different types of service. There seems to be an increased recognition of the value of multi-disciplinary and multi-sector networking, and from the experience of our project, this seems particularly appropriate for HIV.

FINDINGS

1 Standards

- 1.1 We found an impressive level of commitment to achieving and maintaining high standards of HIV services to patients despite significant constraints in resources in certain services. A range of healthcare professionals had developed innovative services which were perceived as being highly supportive by service users we interviewed, both in rural areas where there was a very low prevalence of HIV and in urban centres with much higher prevalence.
- 1.2 A number of project participants felt that the 1998 *Standards for NHS hospital HIV services* were useful and applicable. It was also felt that they needed to be regularly reviewed and updated through an inclusive and transparent process.¹⁷ Some centres were using them to audit their own performance and to provide guidance on how to link with other health professionals if an aspect of service was not provided in their centre. Others expressed the opinion that the standards were designed with large centres in mind and did not feel that they would be able to deliver some of the standards as detailed in the report. However, in each case where a concern about a particular standard was raised, it was recognised after discussion that the standard *could* in fact be met either in the centre concerned, or through collaboration between two or more centres.¹⁸ This was in tune with the *standards document*, which emphasised the need for local flexibility while setting out a broad, generally applicable model.
- 1.3 It was pointed out to us that written standards only exist for limited areas of HIV treatment and care. It was felt that there were many gaps in standards (eg paediatric care, care for HIV in custodial settings)¹⁹ which ought to be filled following an agreed set of principles for quality standards development. It should be possible to ensure that guiding principles run throughout the different sets of standards, and that new developments link in and build on already existing standards so that the different sectors can provide coordinated care.
- 1.4 HIV services throughout the UK have largely grown organically in response to a new disease and a sense of crisis. In most areas these services have centred on local genitourinary medicine (GUM) clinics, whether in the community or local hospital. One of the ways HIV differs from most other STIs is the need for patients to spend some periods of time in inpatient care. Therefore, the relationship between a GUM clinic with regular outpatient work and the local hospital where inpatients will be located is key to understanding service configuration and network development. A lack of coordination between these two aspects of HIV care was found to cause barriers to the development of quality standards. The need to coordinate inpatient and outpatient care for people with HIV should be seen as a major driver for service network development.
 - 1.4.1 The fact that different specialties are involved in leading on HIV care resulted in many different service configurations for outpatient care. Where the lead consultant is from GUM, outpatient care is usually organised through what is commonly termed 'open access'. In practice this means that patients can self-refer, and do not need to be referred by a general practitioner (GP) or other healthcare provider in order to access the specialist clinic. In addition there is an understanding that patients are not compelled to provide their real names or give many private details when attending GUM services and this ethos may be felt

to influence the nature of GUM-based HIV outpatient services. Among service users there is a belief that confidentiality is much greater in these clinics than other forms of NHS care. In practice the differences are not so clear. Where the lead consultant is from any other specialty, outpatient clinics are linked to inpatient care, eg an outpatient clinic attached to an infectious diseases (ID) ward, or respiratory medicine.

- 1.4.2 Different service configurations result in variations for patients in how their care is organised, and in the liaison between inpatient and outpatient care. Because GUM is a specialty which traditionally has not required inpatient care, GUM consultants are rarely on the medical rota in a district general hospital (DGH). Therefore, if the lead HIV clinician is a consultant from GUM there are a variety of arrangements for organising inpatient care. This usually involves the consultant who is on the medical rota that day. We found wide variation in the arrangements for liaison in these instances. In a few cases there was no liaison at all with the GUM consultant and patients with HIV were admitted to the ward of the consultant on the medical rota whether or not it was appropriate for a patient with HIV. This resulted in other agencies (eg social workers and voluntary organisations, or even clinical nurse specialists) not knowing that their patients had been admitted or where to find them in the hospital. In other cases, there was a clear protocol for admittance with guidance for liaison with the GUM consultant and a logical arrangement for providing inpatient care on a specialised ward. There were some instances where GUM consultants were included on the medical rota specifically to ensure efficient admittance of patients with HIV-related illness.
- 1.4.3 If an ID or respiratory medicine consultant had the lead role in HIV, it appeared to be easier to ensure continuity and appropriate liaison between outpatient care and inpatient care because of the routine arrangements already in place for these specialties to handle admissions and inpatient care.
- 1.4.4 In some towns and cities that we visited there were two outpatient centres operating, based respectively in GUM and ID. Inpatient care in these situations was typically in ID. Prior to HAART, inpatients in these situations were not usually referred back to GUM clinics after hospitalisation, because the expectation was that the patient's health would deteriorate rapidly, resulting in more episodes of inpatient care and eventually death. However, since the introduction of HAART, a number of patients as well as GUM consultants felt that it was appropriate that patients be referred back to GUM for their outpatient care. If this did not happen there was a loss of continuity of care. But referring a patient back to GUM raised problems for the consultants (in ID or respiratory medicine) in charge of inpatient care who then did not see individual patients on a regular basis. A number of places that we visited during the project were confronting this problem, and inpatient or outpatient care was being reorganised because of it.
- 1.5 Some single-handed consultants were working under great pressure with few resources. These consultants often had busy clinics in ID or GUM, with HIV forming only a small proportion of their work. The number of visits to GUM clinics in England has doubled over the last decade but the number of GUM

clinicians has not risen accordingly. This had resulted in severe strain on GUM clinics, with long waiting lists for first appointments and extremely high patient caseloads.²⁰ However, because of the complexity of treatment the small number of patients with HIV can take up a great deal of time. It is single-handed consultants, working under pressure and possibly located in rural areas far from the large centres, who often have least resources, including cover from colleagues, to network through professional educational meetings or other such events. Indeed a number of them could not attend our one-day meetings for precisely these reasons. But they need the support of colleagues in the field in order to discuss their caseloads and to deliver a high quality service to their patients.

- 1.6 To a greater or lesser extent, all consultants can experience difficulty in getting cover that enables them to attend educational events, or for annual or sick leave. In some cases there were specific arrangements for cover (eg between Bristol and Bath). Others suggested that time for meetings and networking needed to be specified in a contract with cover provision arranged as the only way to ensure that people with more experience attend such meetings. Some of the larger centres were already doing this. However, it is almost more important for people working in centres with low numbers of patients with HIV, who are least likely to have this kind of arrangement formalised in their contract.
- 1.7 BHIVA guidelines for clinical treatment of HIV²¹ were widely known and appeared to be widely used. People we talked to felt they were clear, user-friendly and included a transparent and accessible system for regular review.
- 1.8 Where specific instances of concern about the quality of local services emerged during the mapping exercise, there were issues about how these could be resolved and in particular who should take lead responsibility. It was often this lack of a clear line of responsibility which had caused the issue in the first place and which subsequently prevented its resolution. In some of the problems we heard about, clinical staff frequently seemed to feel that commissioners had all the decision-making powers, while commissioners expressed that they felt unable to go against the wishes of the clinical staff. Trust managers did not appear to be closely involved in decision-making about HIV care, or the debates between commissioners and service providers. However, they had the power to make some important decisions including, for example, about renewing posts.
- 1.9 There was very little awareness about where negative pressure rooms, required for suspected cases of TB and in particular for multi drug resistant (MDR) TB, were situated. In some cases people cited centres that did not have them. We came across an instance in one area where there had been a case of suspected MDR TB just prior to our visit and no negative pressure rooms could be found. It was felt that other patients and staff had been put at unnecessary risk of infection. In the end the patient had had to be sent to London.
- 1.10 Concern was expressed about the general capacity of clinicians to interpret increasingly complex tests,²² which are essential to the successful medical management of HIV. Professionals in the Public Health Laboratory Service (PHLS) who were returning test results, as well as known 'experts' in the field, were spending a great deal of time explaining results and treatment options to clinicians. Because each test was usually carried out for a unique situation, the support being given along with test results was not always consistently building up into a wider body of knowledge. One consultant working with a small

caseload would only ask for such tests to be carried out on rare occasions. Attempts were being made to share test results more widely so that they would play an educational role. Because of the vital importance of clinicians being able to access rapid information and support around test results it would appear that consideration should be given to making this specialist advice a central service, so that time given to supporting clinicians can be factored in, rather than being an informal service dependant on good will. Networking between consultants could also enable greater sharing of such information.

- 1.11 Because of the reduction in numbers of inpatients, some clinicians from specialties related to HIV were seeing very few patients with HIV. Concerns were raised about how they could maintain their skills. For example, a chest physician might only see a patient with HIV once every two years in a small DGH. One suggestion was that short-term staff exchanges between consultants be established with larger centres. However, this had proved difficult to arrange because of other priorities and, to some extent, funding concerns, as well as the lack of initiative in the trusts and institutions concerned to take this rather innovative step.

2 Networks

- 2.1. We found that there was no common understanding of what the development of service networks involves, and no clearly identified and developed service networks in the areas included in the project. However, there were a number of interesting examples of network development in different areas.
- 2.2 We also found widespread misinformation about the meaning of service networks and the implications of working within them. This varied with, at one end of the scale, people concerned that network development would mean the closure of all HIV services outside large urban centres. In fact, centres treating small numbers of people with HIV are more likely to be able to meet quality standards for their care through liaison with neighbouring centres than alone and we found some excellent examples of this.
- 2.3 A lack of agreed understanding about the meaning of service networks was a barrier to clear transparent communication. Any discussion involved participants speaking about a concept that was understood in many different ways and most participants were unable to hold a clear mental picture of what a network might involve. Because some service providers understood networks as meaning an arrangement whereby one clinical centre had control and power over others, in a type of 'hub and spoke' arrangement, the idea of networks was perceived as threatening to smaller centres. Some smaller services with single-handed consultants expressed some concern that networking would result in larger centres 'swamping' or 'swallowing' smaller centres. However, they themselves pointed out many issues which smaller centres dealt with extremely well, and which would be difficult for the larger centres to cope with.
- 2.4 Some interviewees had a concept of networks as multi-disciplinary mechanisms, involving a range of services within and outside the NHS. Others took the view that networks were only clinical.
- 2.5 There was wide variation in degrees of existing network development. Clinicians and other health professionals in some areas had already initiated ideas or practices leading to network development. In other areas no such discussions or

related activities had taken place. In the areas included in this project, collaborative working patterns had been established between some institutions in a number of places. Some of these were fairly simple involving one or two centres working together over referral arrangements, or three centres, such as Shrewsbury, Walsall and Stafford, agreeing to provide 24 hour cover between them. It is, however, important to note that this was a voluntary arrangement established by clinicians in the three centres. Networking should not be seen by managers as a cost-saving exercise to provide cheap cover, but one where health professionals can collaborate to provide the best possible care for patients. Other arrangements were more complex and represented a significant move towards networking in order to provide quality standards, such as the development of protocols for access to specialist care or inpatient care, or covering the relationship between a teaching centre in a large urban environment and a non-teaching centre in a more rural environment.

Shared care

A clear arrangement for shared care had been established between Burton upon Trent and Heartlands Hospital (Birmingham). This took the form of telephone advice and support between clinicians, and in the case of one patient, where there were complex medical problems, a regular six-monthly visit to Heartlands. This unusual situation proved to be satisfactory to both clinicians involved as well as the patient, all of whom we spoke to. The patient felt reassured at being seen by a large and well known centre but was content with regular care being provided locally, thus avoiding some travel to Birmingham. The clinician in Burton upon Trent found that it was useful for someone else to see the patient occasionally as some underlying trends were picked up, which might have been missed in regular appointments. Heartlands felt the collaboration was useful and made good use of available resources.

- 2.6 These networking arrangements were clearly working well where colleagues were already familiar with each other. For example, in North Yorkshire and the West Midlands, clinicians explained that the fact many of them had trained together assisted in a natural development of collaborative working patterns. This engendered a culture of trust, which has been cited as one of the key ingredients of network organisations.²³ Early experience suggests that networks are set up by enthusiasts who commit energy and commitment.¹⁴ Building on the positive connections between individuals who already collaborate well in a particular area would appear to be the most likely way of creating a group of enthusiastic 'pioneers' to lead the way during the early phases of any particular network development.
- 2.7 In some areas clinical networking was taking place with referral of inpatients to larger centres when there were medical complications. This networking appeared to be rather *ad hoc* and we heard concerns expressed that "patients are often referred too late".
- 2.8 We found few examples of protocols in place for networking or referral of patients, although one example from Yorkshire is given below. Existing networking was usually informal and based on personal contacts. One opinion voiced was that care pathways are the key to successful networking. If agreed pathways are to be established then joint protocols need to be developed.

Models of HIV care through networking: example 1

A busy GUM clinic in Dewsbury, Yorkshire, with a small number of HIV patients, was working in collaboration with the other specialties in the DGH in which it is based. It had also formed a close link with a large, neighbouring, teaching GUM clinic. A flexible and regularly updated protocol clarified the roles of different professionals in the smaller centre, and specified when the larger centre should be contacted for advice, support or access to specialist services. Clinical development was based on evidence emerging from regular monitoring, and the consultant at the smaller centre accessed professional networking meetings to maintain clinical knowledge. The result was a genuine partnership and a standard of care that was appreciated by service users to whom we spoke.

- 2.9 Initiation of a clearly identified and labelled multi-disciplinary network for HIV treatment and care had not taken place in any of the areas we visited at the time of carrying out the project.
- 2.10 Many health professionals we met had extensive experience of participating in networks of various kinds. The HIV field has frequently led to representative groups developing such as the Royal College of Nursing Sexual Health Forum, the National HIV Nurses Association (NHIVNA), the UK HIV Pharmacy Association and the Dieticians HIV Association (DHIVA). Because of the range of specialties involved in HIV treatment and care, some individuals might also be part of other newly developing managed clinical networks such as those for cancer or haematology (and TB in London).
- 2.11 Regional networking was also occurring through educational events taking place in different areas. One example was the monthly Grand Ward Round and weekly Viral Load meeting for all clinicians working in HIV in the West Midlands. In Yorkshire all clinical services were meeting quarterly for clinical audit and professional education. Professional education was occurring through regular meetings at Brighton. In the South East the South Thames Regional HIV Audit Group also provided an important forum for exchange of information. Getting cover to attend meetings or conferences was a serious problem in nearly all of the smaller clinics (see para 1.5). Some interviewees found that the timing of meetings at some centres (eg lunchtimes) made it difficult to attend. In the South West regional audit meetings were taking place for GUM but did not include ID which meant there was no regional HIV grouping. This split was also occurring in other areas and was due to the range of clinical specialties involved in providing HIV treatment and care.
- 2.12 We found that in some areas there was a general feeling of enthusiasm regarding the concept of network development. People were interested and had ideas which they shared readily with others. But we also came across some mistrust. This stemmed from a number of factors. Some of these included a fear of losing independence about who to work with and how that was organised and managed, a fear that the 'interesting' HIV work was going to be redistributed away from smaller centres to larger ones, and a general sense that it was difficult to cope with another concept such as the introduction of networks, when there were so many changes already taking place within the NHS.

Models of HIV care through networking: example 2

Worcester had developed an unusual model of HIV care. It had set up an HIV team which included a lead ID consultant and two GUM consultants. The team was employed by two separate trusts, and operated across three sites: Kidderminster, Redditch and Worcester. All inpatients had been, until recently, admitted to Kidderminster Hospital under the care of the ID consultant. (Kidderminster Hospital was closed for rebuilding and inpatients located at Ronkswood Hospital at the time of our project.) This arrangement meant that no single consultant was working in isolation.

Since the project, we have heard that the Worcestershire HIV (WHIV) Clinic now offers the full range of in- and outpatient services for patients living in Worcestershire and Herefordshire, and for some from South Shropshire and South Birmingham, with inpatients being admitted to the ID & Haematology unit at the new Royal Worcester Hospital. This service has also taken on the role of tertiary inpatient provider for Gloucestershire (see *Models of HIV care through networking: example 3*), and regular clinical meetings are held between staff from the two centres. The WHIV clinic is staffed by one ID and two GUM consultants who share patient care, supported by a multi-disciplinary team.

- 2.13 Even where there was enthusiasm and commitment to developing a service network it was not always clear who should take the lead in initiating the new working arrangements. Because there were uncertainties about who should take a lead in network development, we encountered situations where there was nervousness about appearing to 'take over' network development. This was a clear barrier to network development.

Models of HIV care through networking: example 3

An unexpected example of network development that we came across involved a medium-sized centre in Gloucester, which had asked larger centres to tender for a tertiary role in treating its patients. This meant that the 'smaller' centre in a networking relationship, far from being disempowered, was actually setting the terms for partnership. This model may be of interest to other smaller centres around the country that fear the development of service networks will mean a loss of control for local clinicians.

- 2.14 In various interviews the development of IT was mentioned. Consultants raised the fact that they would appreciate the development of a local computer based communication system. This could assist the sharing of information and possibly transfer of patients. However, some consultants did not have access to a computer. Improving electronic infrastructure was considered by many interviewees to be a prerequisite for successful networking.

- 2.15 There can be local sensitivities about changing service configurations; in particular about whether there should be a 'comprehensive HIV centre' and what role it might play. Three of the urban centres we visited, Leeds, Birmingham and Bristol had (or had had in the past) HIV treatment and care located in two centres in the city: ID and GUM or a combination of both focused on a specialised HIV centre. In both Birmingham and Bristol there were local reviews to determine whether these two services should be centralised, with different outcomes. In Birmingham the two services continued to provide HIV care and in Bristol, HIV care was centralised at one centre, Southmead (ID), and no longer provided in GUM. The service decisions at Birmingham and Bristol provide useful experience for other areas.²⁴

Organisation of services: example 1

An independent review of the two HIV services in Birmingham was undertaken by Birmingham University for the health authority. This review looked at both clinical outcomes and financial impact. The conclusion of this review was that the two services should continue within the same structure, as they provided good value for money and an element of choice for local people with HIV seeking medical care.

We heard a variety of reactions to the outcome of this review from service providers and people using services. Some said that they felt the outcome was appropriate, that the two centres (Whitall Street/Selly Oak and Heartlands) collaborated, that it was beneficial for patients to have a choice of centres to go to, that patients liked it, and that in the second largest city in the UK there should be at least two centres providing HIV care. Others we spoke to said they felt that having two centres for HIV care was not the best way of organising service provision. They raised a number of issues in interviews including concerns that the two centres do not collaborate well enough over city-wide service planning and delivery and that it was hard to discuss these issues openly.

Organisation of services: example 2

A decision was made by the health authority in 1998 to centralise HIV services in Bristol at the ID unit at Southmead. More resources were allocated to Southmead after the change. The centralisation of HIV services in Bristol was an important event, the effects of which were still felt some years later. This was not only in Bristol but also affected GUM professionals throughout the South West.

Reactions to this decision were mixed: on one hand some felt that the service was improved, with all HIV services being provided on one, better-resourced site. However, healthcare professionals in GUM did not feel consulted about the changes and reported that there had been no follow-up exercise to consider the impact of these changes in the subsequent period. They felt that a forum for discussion and planning some joint management of patients would be particularly useful. In addition, while attempts had been made to provide STI screening for people with HIV in the new arrangements, some service users felt they were missing out on regular sexual health checks by getting their HIV care through an ID unit.

- 2.16 In areas of low prevalence, most outpatient clinics will see between 10 and 200 patients with HIV in any one year. These numbers are small compared with London, even though the staff/patient ratios may not actually be that different from centres with higher numbers of HIV patients. Inpatient episodes have been reduced dramatically in most areas because of the success of antiretroviral therapy. An average DGH may see between two and 24 inpatient cases a year. This has substantially changed the organisation of acute care for people with HIV. Some interviewees expressed the view that outpatient units could maintain high quality services with small caseloads, but that inpatient services should be networked in order to ensure that patients were seen by medical and support staff experienced in HIV. It was felt that with the current decrease in inpatients, the necessary expertise could not be maintained in centres with small caseloads. However, there were concerns over the fact that all centres had inpatients who were only diagnosed with HIV after their admission to hospital. Such cases make up a disproportionately large number of the deaths linked to HIV in the UK and demonstrate the need for a broad knowledge of HIV symptoms among hospital physicians who are not HIV specialists.

Clear care pathways

In Brighton when patients living at a considerable distance were discharged from hospital, a shared care arrangement was operating with community-based CNSs. A CNS, ensuring local access for patients and continuity of care, would deliver the regular on-going care in close liaison with the hospital, which played the role of a comprehensive centre for quite a large area. Patients were referred back to the hospital if their health required it. Care pathways were smooth and clearly understood by all parties.

- 2.17 Other interviewees felt that inpatient care was very adequately provided at a smaller centre drawing on the range of specialties provided in the local DGH. They felt that liaison between the HIV specialist at the DGH (usually a GUM consultant) and the relevant specialties such as respiratory medicine, oncology and psychiatry among others, provided adequate care.
- 2.18 Some networking with London was going on in all of the areas we visited. This networking consisted of telephoning for advice, and/or sending people to London for tests and more complex aspects of their care. The decision on whether or not to use London services for local patients was based largely on transport. In some outlying areas (eg York in North Yorkshire and parts of the South West) it is as easy to travel to London as to travel across country to any other large/teaching hospital. Some rural services had shared care with London centres because they had inherited patients who had been using London services before local ones developed or prior to moving into the area.
- 2.19 As well as the availability of transport routes, sheer distance was a significant problem in some rural areas, with specialist services many miles apart and networks needing to cover vast areas. For example, although Penzance and Bristol are both in the 'South West', the distance between them is the same as from London to Leeds. A car is more or less essential for most travel within such areas, if only to reach the train station. This can present challenges to both patients and professionals seeking to share care or organise cross-network events between sites.

- 2.20 We came across some 'patient-led networking', with patients moving from one service to another according to a variety of criteria such as the state of their health, transport, employment, confidentiality or dissatisfaction with services.

3 Multi-disciplinary approach

- 3.1 Although many different health professions are involved in providing HIV treatment and care, we found that the approach to networking was rarely multi-disciplinary. Networking tended to occur within a professional group such as clinicians (possibly including CNSs), commissioners, self help and voluntary groups, related professions such as social workers, mental health professionals, dieticians, health advisors and pharmacists. In addition, professional networks were often operating within specialties such as GUM, ID, haematology, virology and paediatrics. Information was not always shared between these professionals across network boundaries, even when everyone was working with the same patient.
- 3.2 Where a genuine attempt had been made to work collaboratively across clinical professional boundaries and disciplines, service users appeared to be aware of this and appreciative. They expressed the view that this resulted in patient-centred care.
- 3.3 Certain fora had been established in some areas to overcome barriers to joint working and to establish better communication among service providers in HIV. Facilitated events such as the provision of professional education, or HIV planning groups were presented through these fora. In some cases these worked well but in others they were considered not to. In many instances where such fora did exist, some people felt unwelcome, or had not been invited. Some people representing service users told us that they felt they were perceived as 'difficult patients' because they asked questions about treatment and services. Some clinicians told us that they felt they were put 'on the spot' by their patients challenging them about treatment issues in such a public setting. Others chose not to attend, usually because they felt attendance offered no particular benefit to them or their organisation or because they felt excluded in some way.
- 3.4 Because HIV CNSs liaise and collaborate with a range of professionals, they often play a key networking role across the disciplines. Many people with HIV told us they appreciated the ready access they usually had to CNSs, and the flexibility of their roles. Although the CNS post was originally envisaged to provide home care, particularly in terminal stages of HIV illness, the post seemed to have adapted well to the medical changes in HIV, with CNSs now taking an important role in liaising between patients and healthcare professionals in the local DGH over issues such as referrals for inpatient care, medication, access to specialist services, and sometimes with voluntary groups providing psycho-social support. We also found that in many instances CNSs and nurse-qualified health advisors played a very important role in adherence, often being the first point of contact for people who had lost or run out of medication and providing advice, support and information in a flexible and accessible manner.
- 3.5 The post of CNS was not consistent, so that in some areas there were a number of CNS posts spread across a district or region, covering rural areas and linking patients into a range of services. In other areas there were only a few CNS posts, or none at all. In some of these areas, health advisors, many of whom have a nursing qualification, took on a similar variety of tasks and roles to CNSs,

typically in areas where the role was merged (one person had both the responsibility of a CNS and a health advisor) or where there were no CNS posts.

Multi-disciplinary adherence support

In Brighton a patient experiencing first-time prescribing or switching of medication would automatically see a multi-disciplinary team. In addition, there was a multi-agency adherence support project which involved a range of organisations in the Brighton area. This initiative recognised the role of different organisations and professionals in ensuring successful adherence. It was aiming to provide consistent and appropriate support for a range of adherence issues encountered by patients on antiretroviral treatment. The multi-disciplinary nature of this initiative meant that patients on treatment could locate an appropriate response to their needs promptly, thus averting many problems in adherence support.

- 3.6 Where there was a designated HIV pharmacist this was greatly appreciated by clinical staff. Some patients expressed dissatisfaction with a situation where there was no HIV training in pharmacy and they were unable to get the information they required. There were differences in who paid for NHS prescriptions for HIV treatment according to where the prescribing was taking place. For example, where GUM services were located in the community, medication was prescribed through community pharmacists rather than being dispensed through the hospital pharmacy, and this had to be paid for by some patients. In addition, as medication available on a 'named patient only' basis cannot be provided through community pharmacists, the range of medication available to patients who got their prescriptions through community pharmacists had some restrictions.
- 3.7 There were problems accessing mental health services in many areas. Appropriate services were not always available and some clinicians mentioned their concerns about the growth in mental health problems, at the same time as the physical symptoms for many people with HIV were improving. People with HIV spoke to us about the difficulty of adjusting psychologically to improved life chances on new treatment regimes, and that this had in many cases caused depression. The difficulties associated with taking medication also exacerbated mental health problems.
- 3.8 There appeared to be a paucity of HIV social workers in most areas. As a result of policy changes, specialist social workers had largely been 'mainstreamed' into general social work. We heard opinions that this had led to a loss, rather than a broadening, of expertise. Voluntary organisations appeared to be providing much of the social care back-up for patients.
- 3.9 This project did not examine primary health care. However, we did speak to some GPs who expressed the view that there was poor liaison between them and the professionals involved in providing treatment and acute care to their HIV positive patients. Since the advent of HAART and the increasing need for acute services to focus on treatment regimens, monitoring viral load and resistance, and other specialist aspects of HIV care, GPs have become more involved in general health care of people with HIV. We came across some difficulties faced by GPs and their patients when patients accessed specialist care and the GP received no information about, for example, the outcome of a special test or

X-ray, or when their patient was seriously ill in hospital. Patients assumed that GPs were given this information and were consequently puzzled by the breakdown in communication on these occasions.

- 3.10 Networking around particular service interventions such as adherence support ensures more appropriate care and greater efficiency through a wide understanding of problems. For example, in many areas we visited, adherence was treated as more or less a medical issue. However, people with HIV on antiretroviral treatment told us of the many complicated factors in their lives affecting adherence that did not necessarily involve medical problems, but also psycho-social or practical problems. It was difficult for these needs to be met without a more multi-disciplinary approach.

4 Input from people living with HIV

- 4.1 We generally found that service user consultation was unsatisfactory. It was inconsistent, rarely acted on, and people using services to whom we spoke felt that the system was not anonymous enough for them to feel confident in making criticisms. There appeared to be a perception in some health services that people with HIV are vocal and articulate and able to lever considerable pressure as service users, whether or not there were good systems of service user consultation. On some rare occasions this was brought up by people we interviewed to explain why there was no formal consultation system for people with HIV for service planning in their area.
- 4.2 We heard a number of views from people with HIV which valued the high standard of medical services available, or the particular skills of the relevant consultant in dealing with the HIV-related illness experienced by interviewees. Where medical staff had an open consultative style, this was particularly appreciated. Patients also valued using services which were at the 'cutting edge' of HIV care. Sensitive delivery of test results, clear information, the opportunity to ask questions, and an accessible service, were other positive aspects of service provision mentioned by users.
- 4.3 A number of service users expressed concerns about the consequences of the success of the new treatments. They claimed that the doctors only looked at their viral loads and no longer at them as people, or the multiple impact that side-effects might have on their lives. If the blood counts were good they felt that it seemed not to matter to their healthcare providers what else was happening: one said "virological success wins out over quality of life". Others felt that the treatment was being funded by withdrawing other types of social support, which they felt they still needed.
- 4.4 Very few clinics had formal consultation mechanisms with service users. Where they did, both service users and service providers often described these as unsatisfactory. HIV fora with user representation were problematic because the issues raised were often perceived to be personal between service users and providers. This left everybody feeling uncomfortable. Service user representation was perceived to be by a certain type of person with HIV – an articulate 'professional service user'. Yet those who did not fall into this category found it hard to follow meetings and understand the issues raised. In general, we found a frustration about these mechanisms among both the service users and the providers with whom we spoke.

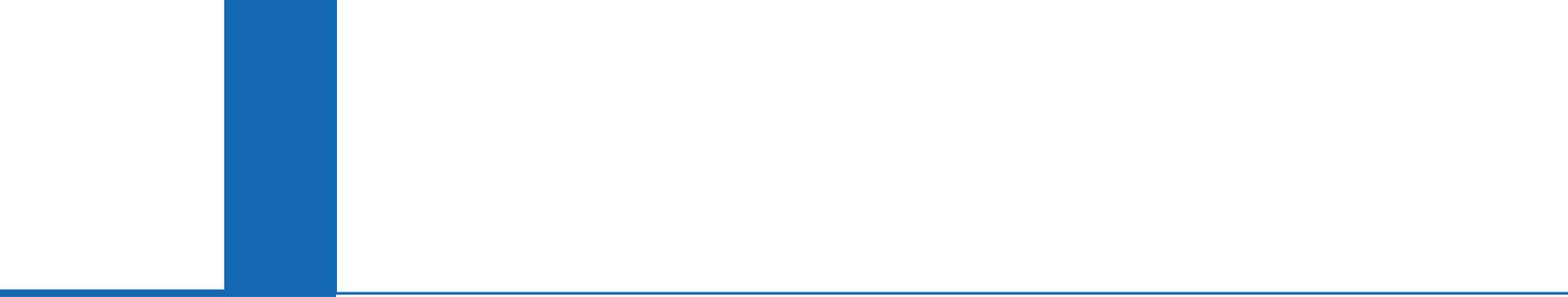
- 4.5 Since our project ended, we have been informed that a user representative has been appointed in Brighton to sit on the management team of the department. This person has responsibility for eliciting service users' views and ensuring these are taken account of in any service developments or used to stimulate change. This post has been acknowledged by the Commission for Health Improvement in its report on the trust as an example of good practice.
- 4.6 There was little evidence that local needs assessments regarding changing epidemiology or the changes due to medication were taken into account when planning service provision. Some people with HIV said that they felt services had not altered to take into account the fact that many people with HIV were now relatively healthy and newly-diagnosed people were not leaving their employment or dramatically changing their lives in the same way that had happened before antiretroviral therapy was widely available. They felt that services should change to take this into account, for example, changing their opening hours to accommodate some evening opening, and routine checks taking less time.²⁵
- 4.7 In some of the areas being mapped (particularly the South East) there were high concentrations of asylum seekers and immigrants of uncertain legal status, in particular around the ports and airports. There are a number of issues which arise when delivering HIV care to this population. When infected with HIV they tend to be late presenters, entering hospital with symptomatic illness but undiagnosed. They may be reluctant to use services continuously because of fears about their legal status, and therefore only use services when in crisis. There are often cultural and linguistic issues to take into consideration. They may be ill-informed about services. Despite their particular needs, involvement of this group of service users in service planning or organisation would, unsurprisingly, be rare.²⁶
- 4.8 Where there was good practice regarding service user participation, people living with HIV were aware of this and in some cases stated that they found that there was a great deal of practical support around issues such as adherence to medication. This contrasted with what we heard in areas with what seemed to be poor service user participation.
- 4.9 Many of the people living with HIV to whom we spoke during the project wanted better and more professional service user participation and consultation, with a commitment to put findings into practice. A number of people said that they would find it helpful if there were posts for people with HIV in clinical services, so that there would be an opportunity to discuss new diagnosis, medication, diet and psycho-social issues. They felt this would be particularly advantageous at the point of diagnosis or moving on to treatment. In some centres we visited, this idea was being considered, but the only clear example which was working well was from the Treatment Support Project in the South West, detailed below.

Collaboration between people with HIV and clinical service provision

A collaboration with service users had been developed in the South West. The Treatment Support Project (run by the Terrence Higgins Trust West and staffed by volunteers with HIV) was collecting and giving treatment information through a 'roadshow' in the Bristol and Bath HIV clinics, and through support to individuals facing decisions about medication. The positive working relationship created between this project and clinicians in Bristol and neighbouring clinics seemed to have been facilitated by the consolidation of hospital services and was important in giving people with HIV a voice in local service planning and monitoring.

5 Commissioning and funding

- 5.1 Our project took place against a background of huge structural change in the NHS, which later developed in ways not yet conceived during the course of the project (with *Shifting the balance of power*). The long-lasting climate of uncertainty was already causing difficulties for HIV commissioners and providers when we talked to them. Within the HIV sector, there had been changes in funding formulae and in medical treatment for HIV, with an impact not only on clinical services but also the voluntary sector where many HIV services had merged or closed altogether. While the changes that were being assimilated during the project were soon superceded, their effects are still relevant here, either because they are more generally applicable to a climate of change, or because they have affected HIV services in a particular and permanent way.
- 5.2 In all the areas where the project worked we found commissioners struggling to keep up with the pace of change, and in particular the uncertainty that was associated with it. In many cases announcements about changes were made many months before the changes were finalised, and nobody was sure what effect they would have. We identified HIV commissioners as key players in service network development, but recent uncertainties and changes in the location of commissioning had meant that many felt in no position to take an authoritative role in developing networks.
- 5.3 As a result of changes and re-organisation at the then health authority level, many experienced HIV commissioners had left or changed posts, or were planning to do so when we spoke to them.
- 5.4 The loss of these experienced commissioners, many of whom had a great deal of knowledge about HIV and had formed close links with providers of HIV care, was leaving a gap at a time when it could be argued that planning medical treatment and psycho-social support had become more complex than at any other time since the HIV epidemic began. It is challenging for a commissioner without specific HIV knowledge to understand the complexity of treatment arrangements.
- 5.5 Guidance from the Department of Health on the definition of specialised HIV treatment and care was not available during the project and there was a general lack of clarity about different commissioning responsibilities. The long-lasting and widespread uncertainty over these changes, and in particular



the lack of clear support and training were a barrier to commissioners taking a strong lead in the implementation of quality standards and/or service networks.

- 5.6 We have identified that strong leadership is an essential ingredient for network development.

LEARNING – FACILITATING FACTORS AND BARRIERS TO NETWORKING

The main learning from the project came through information from providers of HIV healthcare and people using HIV services about the factors which facilitate, and those which present barriers to, the implementation of quality standards and the development of service networks.

We identified the following facilitating factors:

- building on existing relationships
- open dialogue
- access to professional education and information sharing
- good transport systems
- HIV knowledge and leadership qualities in commissioners
- clear leadership
- resources for networking (cover and meeting facilities and time factored in)
- collaborative work patterns.

We found the following barriers:

- long period of change and uncertainty as a result of changes in government policy
- entrenched and competitive professional identities
- loss of HIV expertise from commissioning
- hierarchical structures
- lack of resources (eg cover)
- lack of information sharing and/or poor electronic infrastructure
- poor transport systems
- lack of clear network lead
- suspicion and reluctance to enter into networking arrangements.

In order for quality standards to be achieved throughout the NHS for HIV treatment and care, network development is a necessity. However, the form networks are to take must be clarified and the learning from this project taken into account in supporting local network development and delivery of services.

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- 1 In April 2002, the BMA Foundation for AIDS adopted the name Medical Foundation for AIDS & Sexual Health (MedFASH). Although the project covered by the report took place under the old name, the new name is used in the report except where referring to documents published by the BMA Foundation for AIDS.
- 2 Rogers P A, Whitmore-Overton SE & Evans BG *et al* (1997) Survival of adults with AIDS in the United Kingdom. *CDR Review 7*: R30.
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- 14 NHS South East Regional Office (2000) *Managed clinical networks*. www.doh.gov.uk/stheast/managedclinet.htm
- 15 Chisholm RF (1998) *Developing network organisations: learning from practice and theory*. Boston: Addison Wesley (cited by NHS South East Regional Office 2000, see ref. 14)

- 16 Trist EL (1983) Referent organisations and the development of inter-organisation domains. *Human Relations* 36(3) 269-84 (cited by NHS South East Regional Office 2000, see ref. 14)
- 17 There is now a commitment by the Department of Health to the development of updated standards, written into *The national strategy for sexual health and HIV* (Department of Health 2001:32 para 4.60). The work is being carried out by MedFASH.
- 18 An example of this was one centre which felt that the requirement for a Comprehensive HIV unit to have five medical senior house officers (SHOs) whose job descriptions included a remit for HIV (BMA Foundation for AIDS and the Centre for Research on Drugs and Health Behaviour 1998:27) was too demanding for the size of the centre. However, after discussion it was clarified that these SHOs were not expected to be full time specialists in HIV, but to have some training and a remit for HIV included in their work. Indeed the *standards document* specifically states that they would be expected to work under appropriate supervision at all times.
- 19 The completed guidelines for pregnant women and the prevention of mother to child transmission which have been included with the BHIVA guidelines in 2002 are a welcome expansion into specific areas of care.
- 20 PHLS, DHSS & PS and the Scottish ISD (D)5 Collaborative Group (2000) *Trends in sexually transmitted infections in the United Kingdom, 1990-1999. New episodes seen at genito-urinary medicine clinics*. London: Public Health Laboratory Service.
- 21 British HIV Association (BHIVA) guidelines for the treatment of HIV-infected adults with antiretroviral therapy. www.bhiva.org
- 22 eg Viral load tests, resistance testing and therapeutic drug monitoring (TDM). Increasing complexity of such tests is expected in the future.
- 23 Williamson OE (1975) *Markets and hierarchies – analysis and anti trust implications. A study in the economics of international organisation*. New York: New York Free Press (cited by NHS South East Regional Office 2000, see ref. 14)
- 24 Both situations are written up in more detail in area reports for the West Midlands and the South West which are available from the Medical Foundation for AIDS & Sexual Health.
- 25 In addition many people with HIV with whom we spoke, who had considered returning to work or indeed had returned to work, had found the process complicated and financially disadvantageous. They had concerns about what would happen to the social and welfare benefits they had entitlement to, if and when they became ill again. Going back to work involved a major rethink of life aims, particularly for people who had not been expecting a healthy future. One service user whose health was very volatile and realised he would be financially worse off if he went back to work said “I am in a practical and psychological trap. I’ve made a physical recovery – for what? I fear discrimination. I am worried all the time about coming out as someone with HIV. I just want to get on with my life”.
- 26 This project took place before the policy on dispersal of asylum seekers was implemented, and it is likely that the problem described here is now more widespread.



APPENDIX 1

Methodology

The **Networking and standards for NHS hospital HIV services project** gathered information in four areas of England based on the NHS regions as they were during the period of the project (1999-2001): parts of Yorkshire, parts of the South East, the whole of the West Midlands and of the South West.

We mapped services in the areas we were working in, through semi-structured interviews with individuals, or groups of individuals, who play a role in HIV treatment and care. The results of these were compiled into a report for each area. These were then used as a basis for a one-day facilitated meeting in each area.

Mapping

The aim of mapping was to identify key players in HIV care: commissioners, clinicians and other health professionals, voluntary organisations and, where possible, people with HIV using clinical services. Face to face interviews were carried out with a selection of people in each area, and telephone interviews carried out with others. Altogether we spoke to 143 people, as follows:

FIGURE 1: PEOPLE INTERVIEWED AS PART OF THE MAPPING PROCESS IN EACH AREA.					
	Yorkshire	South East	West Midlands	South West	Totals
Consultants	6	8	16	8	38
Commissioners	3	5	3	1	12
Voluntary groups	4	3	5	5	17
People with HIV using local services	8	2	14	17	41
Clinical nurse specialists	3	8	2	5	18
Clinic nurses		3	1	2	6
Pharmacist	1	1			2
Other	3*	5**	1***		9
Total	28	35	42	38	143

* Researcher, Social Services, CCDC.
 ** HIV services manager, health adviser, 2 health promotion workers and a finance officer.
 *** 1 GP.

The mapping process was particularly useful for getting in-depth information about an area. It enabled a process whereby there were different sides to the same story recorded. Using a semi-structured interview schedule allowed a number of issues to emerge, which we had been unaware of at the beginning of the project.

One of the reasons for locating the networks and standards project out of London was that earlier work on standards and networks was perceived to have been geared towards larger centres, and in particular those in London. Some consultants from smaller clinics said that they felt they had little opportunity to feed in to consultation processes because of lack of time and resources. The mapping exercise was inclusive, giving a voice to those living and working in areas of low HIV prevalence.

While the mapping process was intended as a method for collecting information, one of the unexpected aspects was that we found we were also giving information out about the meaning of service networks. Individuals had space to express their concerns and ask questions about national issues such as the development of the national sexual health and HIV strategy, funding structures and other topics of national importance. As well as this, the simple fact of visiting the clinics and other services gave the project workers a broader picture of HIV services.

As can be seen from figure 1, the profile of interviewees in each area we visited was different. The data collected in the interviews were not intended to be exhaustive but to give a 'flavour' of what was going on in each area, some of the different attitudes towards quality standards and service networks, as well as a deeper understanding of the difficulties and advantages of running services in more outlying parts of the country. People with HIV were contacted through voluntary and self-help groups and in some cases through clinical services.

Facilitated one-day meetings

The facilitated one-day meetings were designed to create a space where service networks could be discussed and progressed in response to local issues. The project did not have a pre-set agenda for the meetings apart from the intention that further progress would be the responsibility of local stakeholders who participated. The multi-disciplinary approach used in the mapping was carried on in the local networking meetings. Many of those working in the field of HIV commented on how fruitful it was to meet professionals from other sectors. In some cases, participants had very little idea of what other services were currently doing or planning for the future, even if they were quite close geographically, and in some cases had already established a working relationship.

All of the meetings notes were reproduced and circulated to the people who attended the meetings.

Area reports

1 Yorkshire

In Yorkshire we carried out interviews in the five then neighbouring health authorities: Leeds, Calderdale and Kirklees, Bradford, Wakefield and North Yorkshire. There were two centres providing HIV care in Leeds, and a number of GUM clinics providing HIV care throughout West and North Yorkshire. People interviewed are detailed above in figure 1. Leeds is the geographical centre of the area and had the largest number of people with HIV attending its services. There were two clinical centres in Leeds, one a GUM clinic and the other an ID unit, and both had become part of the same NHS trust. At the time of the project, health professionals had not discussed the issue of where a comprehensive centre might be located in the area, or if it could be two centres.

A local networking event organised using the Open Space format was held for West and North Yorkshire on July 17th 2000 and attended by 23 people working in the HIV field and/or living with HIV and AIDS. An initial planning group meeting was held with interviewees from the mapping who had appeared most interested in progressing networks or who held key roles. The action for the day was agreed. During the day each workshop produced recommendations and these were circulated to all those who attended. These were designed as an action plan for local network development, with local responsibility identified for carrying out the recommendations.

2 South East

In the South East we focused on Brighton as the centre of a network and worked outwards encompassing Kent, Surrey and Sussex. The people interviewed are listed in figure 1. The South East has no natural geographical centre and the proximity of the whole former NHS Region to London resulted in an imbalance of caseloads at services. Transport systems are all geared towards London and it was often easier for people with HIV to use services there than in their local area.

In the area mapped we found wide variations in the prevalence of HIV infection. Brighton had an unusually high HIV prevalence due to a number of factors, the most important of which was the large gay community in the town. There was one main provider of HIV care in Brighton and this was a GUM centre specialising in HIV care. At the time of the project, numbers attending HIV clinics had increased greatly, possibly as a result of gay and HIV positive newcomers moving to Brighton attracted by its reputation as a gay centre as well as the reputation of HIV services there.

In the rest of the South East, the HIV prevalence tended to be low and varied slightly throughout the area. Care was provided through local GUM clinics. Some of these were extremely busy and where single-handed consultants were working on split sites they could be carrying a relatively high caseload of patients with HIV. In some cases there was also a lack of clinical assistance, which exacerbated the difficulty. We found a general feeling that funding was unfairly distributed because of uneven caseloads.

A local networking event for the South East organised using the Open Space approach was held on 24 July 2000, and attended by 49 people working in the field of HIV and/or living with HIV and AIDS.

3 West Midlands

In the West Midlands mapping was carried out over the whole area focusing on Birmingham as the centre. The 42 people interviewed are listed in figure 1. The West Midlands Region had, at the time of the mapping, 13 health authorities. A number of these were small and clustered in the conurbation around Birmingham. This had implications for services, as people living in this area were able to access a range of GUM and HIV services due to the relatively close proximity of the towns and accessible transport systems. Birmingham itself forms a clear geographical centre to the region. The other health authorities covered some urban centres, but also had some rural areas, including locations with sparse population and poor communication systems.

HIV services in most of the West Midlands were provided through GUM. There was a variety of arrangements for admitting inpatients most of which involved liaison between the GUM consultant and the consultant on the medical rota. All four GUM consultants at Selly Oak in Birmingham had direct admitting rights and responsibility for inpatients. There were also some departments of ID involved in HIV care, notably at Heartlands in Birmingham, Stoke on Trent and Kidderminster/Worcester. In some places there were quite complex arrangements for providing HIV care, involving a range of health professionals from different trusts, different directorates and different specialties. Heartlands Hospital had formerly been established as a regional centre of excellence for

i Birmingham, Coventry, Dudley, Herefordshire, Sandwell, Shropshire, Solihull, North Staffordshire, South Staffordshire, Walsall, Warwickshire, Wolverhampton and Worcestershire.

HIV care under a previous NHS structure when the then Regional Health Authority played a leading role in organising services. Since the development of the internal market in the NHS, the hospital's regional role had changed and Heartlands was no longer an official centre of regional expertise, but one of a range of providers of HIV services in and around the city of Birmingham. One interviewee commented to us that, in a sense, the development of the internal market in the NHS had reduced a formal networking arrangement in the region.

Many clinicians told us that they felt the fact that the majority of the consultants in the West Midlands working in GUM and HIV had trained together in Birmingham, and therefore knew each other well, was a great advantage for networking. Fellow consultants in neighbouring clinics were a natural source of advice and support.

A local networking event for the West Midlands was held on 2 March 2001 and attended by 15 people working in the field of HIV and/or people with HIV and AIDS.

4 The South West

In the South West mapping was carried out in the former health authorities of Gloucestershire, N & E Devon, Dorset, Cornwall, Avon, Wiltshire, S & W Devon and Somerset. The 38 people that were interviewed are listed in figure 1.

The South West has no natural geographical centres. In addition transport was difficult and some areas were very isolated. In the Northern part of the region, Bristol acted as a centre and indeed some networking relationships in and around Bristol had been formally developed at the time of the project. Some services at the periphery of the region had network links with services in other regions, such as Swindon with Oxford or Cheltenham and Gloucester with Worcester.

Like Leeds in Yorkshire and Birmingham in the West Midlands, Bristol had previously had two centres providing HIV care, one a GUM centre and one an ID unit. However a decision had been made by the health authority to tender for only one of these to continue to provide HIV services. The ID unit had won the tender and HIV services had since been concentrated in the ID unit at Southmead Hospital. This decision had had a number of consequences both positive and negative, some of which are documented in the main body of the report. These are important because other urban centres may or may not be considering consolidating services in this way.

Two local networking events were held for the South West on 5 March 2001 in Plymouth and on 9 March 2001 in Bristol. They were attended by a total of 23 people working in the field of HIV and/or living with HIV and AIDS.

Throughout the South West we heard a great deal about the problems of networking as a whole region because of the geographical and transport difficulties. It was felt that there should be separate networks in the northern and southern parts of the region. Participants in the Plymouth meeting perceived that it was difficult to identify a location for a comprehensive centre in the southern part of the peninsula and after sharing their doubts about this, the people at the meeting started to discuss the possibility of creating a network with no centre, which genuinely shared skills and expertise throughout the services in the area. A map of a patient care pathway was created by those at the meeting, showing the services and skills in the area. Participants commented on how many specialist skills and services were available in this outlying rural area if resources could be shared.

APPENDIX 2

Abbreviations

AIDS	Acquired immune deficiency syndrome
BHIVA	British HIV Association
CNS	Clinical nurse specialist
CRDHB	Centre for Research on Drugs and Health Behaviour
DGH	District general hospital
GP	General practitioner
GUM	Genitourinary medicine
ID	Infectious diseases
IT	Information technology
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
MDR TB	Multi-drug resistant tuberculosis
MedFASH	Medical Foundation for AIDS & Sexual Health
NHS	National Health Service
PACT	National Association of NHS Providers of AIDS Care and Treatment
PCT	Primary care trust
PHLS	Public Health Laboratory Service
StHA	Strategic health authority
SHO	Senior house officer
STI	Sexually transmitted infection
TDM	Therapeutic drug monitoring
TB	Tuberculosis

APPENDIX 3

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