WHERE THE PATIENT WAS KING?

A study of patient choice and its effect on five specialist HIV units in London

Ruth Thorlby

Patient choice has been central to the Labour government's recent NHS reforms, along with a new payment system that rewards hospitals that are attractive to patients. Will these reforms make services more responsive? This paper is a case study of specialist HIV/AIDS units, where patients have always had a choice about where to go. A sample of patients and staff from five London units were interviewed about choice. Senior staff believed that the freedom to move *did* have an effect on the way they designed some of their services. Most patients valued the right to choose, but few chose to travel or change their hospital.

Published in the UK by the King's Fund

Charity registration number: 207401

First published 2006

A catalogue record for this publication is available from the British Library.

ISBN 1 85717 535 2

Available from:

King's Fund
11–13 Cavendish Square
London W1G 0AN
Tel: 020 7307 2591
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www.kingsfund.org.uk/publications

Edited by Jennifer Bew
Typeset by Grasshopper Design Company
Printed in Great Britain by CGI Europe

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Acknowledgements

I would like to thank the staff and patients who contributed to this study. Owing to the confidentiality of the research, I cannot name any individuals, but I would like to acknowledge the considerable effort and time put in by staff on my behalf and the generosity of patients in both giving their time and sharing their stories. A number of people also gave their time in commenting on drafts. I would like to thank the following: John Appleby, Tony Harrison, Jennifer Dixon and Rebecca Rosen.

Introduction

Extending choice for patients has been a central aim of the Labour government's reform of the NHS in England since it was first outlined in the NHS Plan in 2000 (Department of Health 2000b). Although choices in health care may be exercised at any number of levels (choice of GP, choice of treatment), the first significant choice being offered to patients is that of hospital. From January 2006 a 'menu' of four or five hospitals is being offered to nearly all patients being referred by their GP to see a consultant; this will potentially affect 10 million patients annually (Department of Health 2004b, Department of Health 2005).

The purpose of expanding choice for patients goes beyond responding to consumer demands. The policy has been designed to allow those choices to act as a lever on providers too. This has been achieved by changing the way that hospitals are reimbursed for their work. Since 2003 hospitals have been progressively moving from a system of block contracts to one in which each admission attracts a tariff or payment, a system known as Payment by Results (PbR) (Department of Health 2003b).

Taken together, these two reforms represent a profound change to the NHS. The architects of the reforms claim that patient choice will create an NHS that is more efficient and will push providers to become more responsive to the needs of the individual.

So far there is limited evidence to show how patients and providers will respond to these initiatives. There have been some pilot schemes (discussed in greater detail below) and some limited research on patient behaviour, yet it remains to be seen how providers will respond, how many patients will choose to move, for what reasons, and with what information.

Although 'patient choice' has been presented as a new policy for the NHS in England, there have been areas where patients have exercised a degree of choice over their providers in the past, including choice of GP practice and, in some areas, choice of maternity care. But these choices are not universally offered and were not accompanied by a payment system that directly linked patient numbers to reimbursement. However, in one specialist area, the right of a patient to choose where to be treated was routine, and a payment system evolved that does appear to have added some incentives to providers based on the choices made by those patients. This case is the care and treatment of people with the human immunodeficiency virus (HIV). From the mid-1980s to the mid-1990s, specialist units were created within hospital trusts to treat people with HIV. Care of patients with HIV/AIDS evolved in the specialty of genitourinary medicine, which had a tradition of 'open access' and confidentiality dating back to the 1920s (Berridge 1996). From the first appearance of the virus in the United Kingdom, people with HIV had the right to refer themselves to any HIV unit of their choice and could leave whenever they chose, to go to another unit, or even choose not to be treated. A funding system evolved to respond to this unusually high degree of patient choice, which rewarded providers on the basis of the numbers of patients they treated. Because the bulk of HIV/AIDS cases was (and still is) in London, many of the specialist units were built in London, allowing many patients a range of units to choose from.

This study examined a sample of HIV patients and care providers in London to see whether their experiences might generate some evidence relevant to the wider policy of patient choice. A key aim of the study was to investigate the hypothesis that underlies the current policy initiative: if patients have the ability to vote with their feet (and their decisions come with a sufficient financial incentive), does it prompt providers to change their behaviour?

Background

Origin and development of patient choice policy

In theory patients have always had a degree of choice in the NHS, but since its foundation the NHS has been characterised as an institution in which the provision of choices for patients was a low priority (Klein 2001, Stevens 2004).

The idea of patients having a more active role as 'consumers' was first developed by the Conservative government in 1991, embodied in the *Patient's Charter* – a list of rights and entitlements that patients could expect – followed by the publication of performance information designed for public consumption (Baggott *et al* 2004). However, as one historian of the NHS has pointed out, even under the Conservative government's internal market reforms, patients were given very few new opportunities to make choices themselves (Klein 2001).

On gaining office in 1997, the Labour government dismantled the internal market reforms (although leaving intact the separation between commissioners and providers of services), modestly increased funding, and continued the top-down managerial techniques developed by the Conservatives, focusing on performance management and targets (Appleby and Coote 2002). The focus of policy was not to give patients a proactive role over their care.

Between 2000 and 2001 two things changed. First, the government announced an unprecedented increase in spending on the NHS, which will be sustained until 2008. Second, it also embarked on a different kind of reform, one that implied a more radical market-inspired model than the Conservatives had attempted and that envisaged a role for patients as active consumers of health care, which went under the name of 'patient choice'.

Indications of a policy shift towards greater patient choice was apparent in the NHS Plan, the blueprint for reform published in 2000, and was rapidly developed thereafter. By 2002 the policy had taken shape. As a first step, patients were to be offered choices about where they wanted to be referred for their first outpatient appointment (and by extension any non-emergency surgery or treatment if needed); hospitals were to be paid according to the number of patients they treated; new private sector competitors were to be allowed into the market; and failing hospitals would be allowed to 'exit' (Department of Health 2002). In addition, the government promised to extend 'choice' beyond the narrow confines of elective surgery, and promised more choice in primary care, mental health services, maternity services and palliative care (Department of Health 2003a).

At its root, patient choice and the accompanying financial reforms represent a shift in thinking about what motivates public-sector professionals. In the case of the NHS, the Labour government has concluded that, subjected to the 'normal' array of professional motivations, system incentives and regulations, providers of care could also be 'inefficient, variable in quality, self-interested and unresponsive to patients' preferences' (Stevens 2004).

The most obvious manifestation of unresponsiveness has been long waiting times. In fact, when the detail was added to the patient choice policy in 2002, bringing down waiting times was the primary aim:

> *Over the next four years, starting this year, the Scandinavian system will be progressively introduced across the NHS in which patients are given information on alternative providers, and are able to switch to hospitals that have shorter waits.*
> (Department of Health 2002)

Since 2002 waiting times have fallen, mostly as a result of stringent targets set by the government and backed by tough management, including both rewards and sanctions from the centre. The government is now expecting patients to make choices not solely based on decisions about who can treat them soonest.

> *We all know that as waiting times have been brought down – already a big achievement – patients' expectations have moved on. Of course they still want shorter waiting times – and we've still got more, much more to do. They are a necessary condition of an outstanding health service. But they're not sufficient. Patients want to be cared for as individuals, treated with dignity and respect, made to feel welcome, and certainly kept safe.*
> (Hewitt 2005b)

Success for providers in this competitive environment will bring extra resources to the institution (rather than the individual clinician), and failure – at the extreme – could mean the closure of the hospital. The argument has most recently been rehearsed by the Secretary of State for Health, Patricia Hewitt.

> *If a hospital fails to provide the service that people want and expect, some patients will choose to go elsewhere. And under payment by results – which we've started to introduce this year – money will follow the patient. All this creates a very sharp incentive for hospitals to improve the quality of care they provide – and an equally sharp challenge to the medical profession to change old vested interests and protective practices if they are holding back patient care.*
> (Hewitt 2005a)

Greater efficiency and quality are only two of the expressed rationales behind the reforms. Others include responding to a changed society that expects more choices per se, and delivering greater fairness by extending choices to everyone, not just the better off or the better educated.

> *Choice is important is because – far from entrenching inequality – it will help us create a more equal society. We are a progressive party – and our goal should be to democratise choice. We want to spread individual choice and build collective voice in the NHS.*
> (Hewitt 2005a)

Patient choice: the evidence base

So far there is not a great deal of evidence to shed light on what sort of choices patients might make now (when choice at the point of referral is being offered to all patients) and on what scale. The government has consistently cited evidence from the London Patient Choice pilot (LPCP) scheme, which offered patients a choice of quicker treatment at an alternative hospital if it looked as if their waiting time might exceed six months. A clear majority of patients – 67 per cent – took up the offer. However in this project all patients received free transport to facilities and a dedicated Patient Care Advisor to help them make the choice of hospital. The national planned scheme has neither (Coulter *et al* 2005). In addition, the LPCP (and other early experiments in choice such as the heart surgery scheme) involved patients already on inpatient waiting lists, with the offer of choice being a guarantee of quicker *inpatient* care. The new system offers a choice of four hospitals for a first *outpatient* attendance.

More recent figures suggest a much lower uptake of a national scheme to offer choice to people waiting more than six months for surgery – 20 per cent (Department of Health 2004a). This is consistent with experience in other countries where choice of speedier treatment has been offered: relatively few patients appear to take it up (Thomson and Dixon 2004).

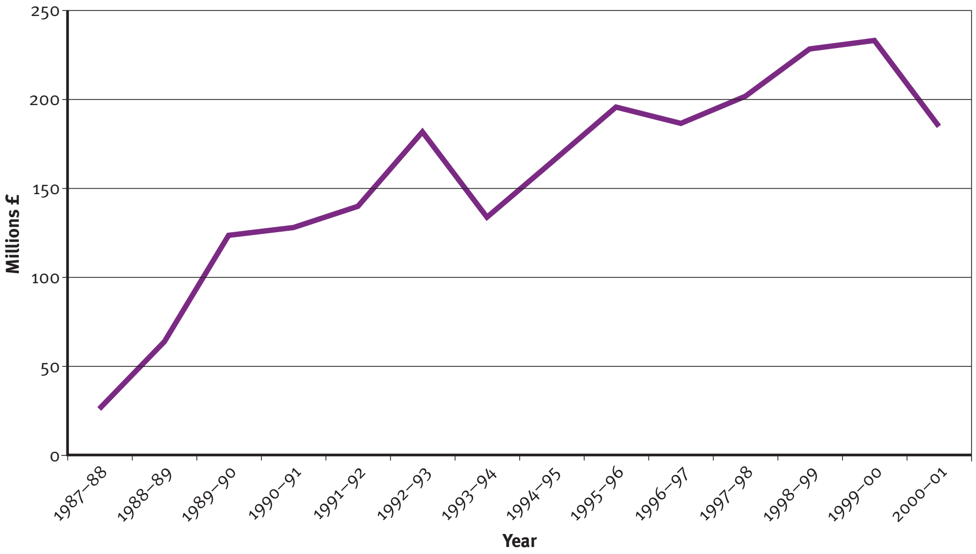
Recent research has suggested that NHS patients will place the reputation of the hospital above waiting times in their decision about where to be treated (Burge *et al* 2005), but there is no clear picture as to what will inform patients' sense of 'reputation'. The NHS is developing more detailed information about, for example, car parking facilities, the availability of public transport or ward cleanliness to help inform patients' choices in the short term.

The context: HIV/AIDS in the United Kingdom and the development of services

The development of HIV/AIDS and the response of the UK government has been well documented (Berridge 1996). News of the first cases of a mysterious disease affecting gay men in the United States began to reach the United Kingdom in 1981, and the first half of the decade was characterised by self-help action from voluntary-sector groups and pressure on policy 'from below'. Although the government was later to step in and play a major role, this voluntary-sector contribution remained a defining feature of the HIV story. Voluntary- and community-sector groups continue to play a major role in providing a high level of information and support to patients, which is still unusual in the context of the NHS as a whole.

Policy at government level began to take shape from 1985. The government first allocated funds for the treatment and prevention of HIV/AIDS in 1986. As a historian of the period points out, the initial cases of HIV/AIDS were few in number. By 1986, 335 cases of AIDS had been reported and 170 of those patients had died (Berridge 1996), but some of the mathematical models of the epidemic were predicting 20,000–40,000 deaths a year from AIDS over the next 40 years (Berridge 1996). The pressure on the NHS was predicted to be enormous, and so funding was greatly increased amid high levels of public and media anxiety about the virus, leading to a tenfold increase in resources to health authorities for treatment between 1985 and 2000 (*see* Fig 1, overleaf).

1 **ALLOCATIONS TO REGIONAL HEALTH AUTHORITIES FOR THE TREATMENT AND CARE OF HIV/AIDS 1987–2001**



Source: Hansard Commons Written Answers 14 November 1990; 29 January 1997; 6 July 2000

The proportionate increase in funding for treatment (prevention and research came out of a separate funding stream) grew much faster than did the new cases over the same period, leading to a situation where 'it seemed as though more money was pouring into AIDS than the regions and districts knew what to do with' (Berridge 1996).

Funding was channelled through regional health authorities, who contracted with hospitals with HIV units, based on the number of live AIDS cases they treated per year (House of Commons 1992). In England, until the early 1990s, there was a concentration of treatment services in London, in three hospitals in particular (St Mary's, the Middlesex, and Charing Cross and Westminster). By 1990, according to the National Audit Office, over 65 per cent of patients being treated at these three hospitals had travelled from outside the health authorities in which they lived. The same report noted that services were less developed elsewhere: 'patients are consequently attracted to the London districts by their reputation for high-quality care' (National Audit Office 1991).

This concentration of resources in London was also criticised for being inequitable and lacking in transparency (Tolley and Maynard 1990). Further controversy arose in 1991, when it emerged that money intended for HIV/AIDS had been channelled into 'other activities' as a result of a significant underspend (National Audit Office 1991). For the purposes of this study it is important to note that services to treat HIV/AIDS were being developed against a backdrop of substantial increases in funding, at least until the mid-1990s.

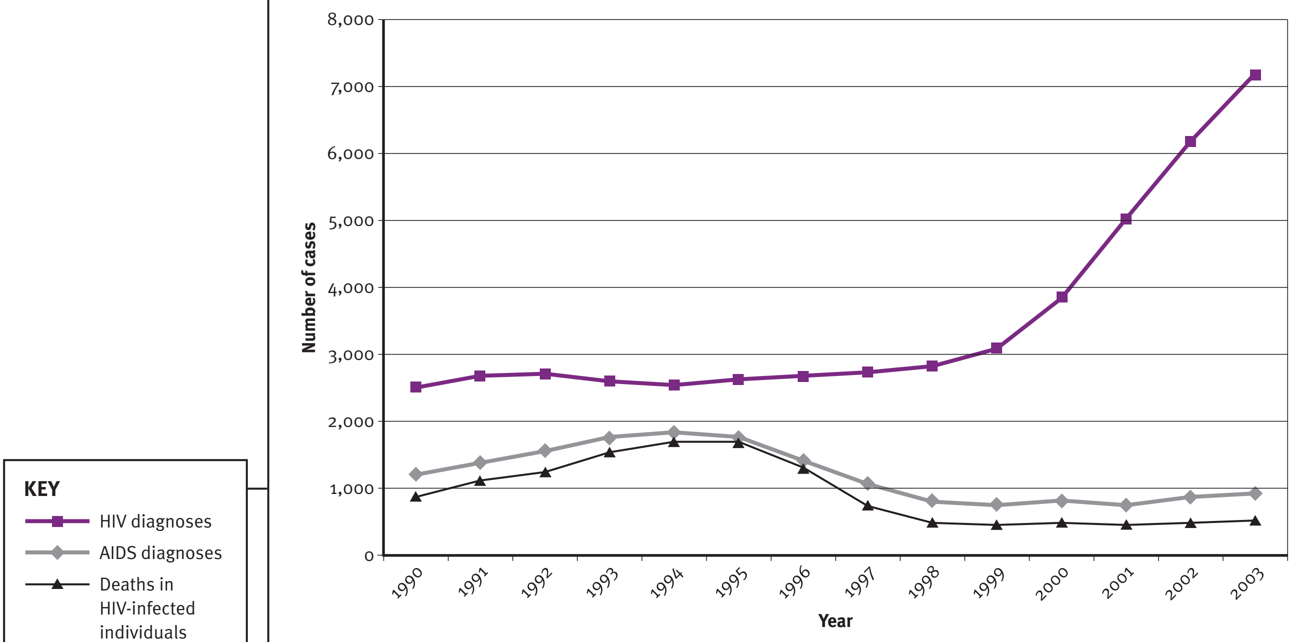
Other specialist units began to develop in London from the early 1990s. Most were grafted on to genitourinary medicine (GUM) clinics, but some took root in other settings, including thoracic medicine and infectious disease units. These units, like the pioneering HIV/AIDS units, offered specialist care on both an inpatient and an outpatient basis. A survey of health districts in 1995 in England, Wales and Northern Ireland revealed continuingly high levels of mobility: 44 per cent of patients were travelling outside the health district in which they lived to access treatment (Molesworth 1997).

Many of the units built wards specially for the care of severely ill patients, who had often encountered high levels of prejudice on open NHS wards. In the early stages of the epidemic, the virus was lethal: death rates were high, and the tradition of care that evolved was holistic and palliative in nature, giving a greater role to nursing and non-medical staff. During this period a cohort of highly motivated doctors and nurses, many of them gay themselves, emerged in the central London units.

Pressure on providers by voluntary groups was sustained, with some groups operating inside hospitals (for instance Frontliners at St Stephen's, now the Chelsea and Westminster NHS Trust). This generated considerable charitable donations to improve facilities, but the groups also demanded access to clinical trials and to alternative therapies. The social stigma experienced by many AIDS sufferers in the early days also generated pressure for help with social security benefits and other non-clinical aspects of care.

From the mid-1990s, there were two key developments. First, in 1996 the first highly effective antiretroviral drugs emerged which led to a drop in both the death rate and cases of AIDS. The second was a gradual increase in the number of new cases of HIV, particularly among heterosexual men and women from African backgrounds, which accelerated dramatically by the end of the decade. The shifting ratio of new HIV diagnoses to AIDS cases and deaths can be seen in the figures for the United Kingdom, shown in Figure 2.

2 **HIV DIAGNOSES, AIDS CASE REPORTS AND DEATHS IN HIV-INFECTED INDIVIDUALS, UNITED KINGDOM, 1990–2003**



Source: Communicable Disease Surveillance Centre (HIV and STI Department) Health Protection Agency Centre for Infections, and Scottish Centre for Infection & Environmental Health. Unpublished Quarterly Surveillance Tables No.68, 05/3 Tables 2 and 3a

Despite the obvious increase in cases by the end of the 1990s, the clear evidence of effective drug therapies heralded a new phase in the government's response to HIV/AIDS, an end to the 'war' footing (Berridge 1996), and the emergence of what has been called the 'normalisation' or mainstreaming of HIV care within the NHS (Bonell 2000). Ring-fenced funding was stopped in April 2002, and since then primary care trusts (PCTs) have been responsible for commissioning both prevention and treatment services on the basis of need. In the case of London, the 31 PCTs have commissioned jointly as a consortium.

The period since 2000 has not been comfortable for patients or providers of HIV services, in either the NHS or the voluntary sector. The number of cases has been increasing, and so too have drug costs. Stigma and exclusion are still experienced by many people with HIV, including those from ethnic minorities and gay patients (Atrill *et al* 2001). The demand for non-clinical, holistic care remains high, but the funding is reducing, affecting both the voluntary and the statutory sectors (House of Commons Health Committee 2003).

Nevertheless, the experience of HIV providers and patients has been instructive for the NHS. A recent scrutiny of HIV services in London drew attention to the contribution of specialised units to NHS standards, before embarking on a litany of the problems facing the sector.

> *We applaud clinicians and hospital staff for their work in creating services that are patient centred, even before the emergence of the NHS Plan.*
> (London Assembly Health Committee 2004)

HIV/AIDS: the funding structure

Funding arrangements for the treatment and care of people with HIV/AIDS necessarily evolved within the constraints of preserving the principle of 'open access' for patients. For most of the late 1980s and 1990s, funding was channelled directly from the Department of Health to health authorities, who then reimbursed hospitals on the basis of the numbers of live AIDS cases seen within a year (Cosgrove *et al* 2001a). In 1998, the department changed its funding criteria to include new HIV patients 'who subsequently go on to take prescribed combination therapy during that financial year' as well as the old definition of paying for those 'with symptomatic HIV disease or AIDS in treatment', to reflect the cost of the new antiretroviral drugs (Department of Health 1998).

The amount allocated to hospitals, although based on the numbers of patients being treated, varied substantially across regions, leading to a review by the Department of Health in 1998 (Cosgrove *et al* 2001b). The review attempted to map the amounts actually spent on the treatment and care of people with HIV/AIDS and allocate funding based on their district of residence rather than the area in which they were treated, adjusted for market forces (Cosgrove *et al* 2001a). From 2000, health authorities were expected to commission services from hospitals on behalf of their local populations, but since patients chose where to go, the Department of Health acknowledged that health authorities would need to commission services for patients on the basis of historical patterns of attendance (Department of Health 2000a). Allocation decisions used data from the Survey of Prevalent HIV Infections Diagnosed (SOPHID), which recorded both the place of treatment and the district of residence. Hospital trusts returned data to SOPHID twice a year, recording the numbers of patients in treatment.

The funding system differed from the current Payment by Results (PbR) system in that there is no national tariff for treatment episodes and trusts were reimbursed with a delay of a year. Nevertheless, even though the precise formula for allocation of resources per capita appears to have been opaque through much of the 1990s, it does appear to have been clearly linked to the number of patients treated and, against the background of increasing resources for much of the 1990s, offered a clear incentive to specialist units to expand.

The study

Methods

Given the aims of the study, a sample of HIV units was needed that reflected the variety of units operating in London, in terms of both size of units and the characteristics of patients. A recent study lists 25 centres providing treatment and care for HIV in London (London Specialised Commissioning Group 2005). Purposive sampling was used to select a list of ten, which included the largest specialist inner London units (with large cohorts of gay male patients) and some smaller units serving predominantly African populations.

Five units based in five NHS hospital trusts agreed to take part. Two units were small, treating between 300 and 400 patients each, and three were large, treating between 2,000 and 5,000 patients each.

The core of the research was based on in-depth, face-to-face interviews with a sample of five staff members and five patients at each unit. The sample size was designed to be sufficient to identify a range of responses from individuals to each question, but not large enough to generalise numerically from those responses. Further work will be necessary to achieve that aim.

In order to test whether the choices of patients had an impact on the service, a mixture of staff were interviewed in each trust, but always including the head of unit, one or two senior physicians, nursing staff, non-nursing professionals, such as counsellors, and receptionists. In one case only, a unit had a dedicated manager, who was also interviewed. A key selection criterion was several years' experience in the unit (at least four years), to allow the role of patient choice on the development of services to be explored.

Only patients who had switched units were selected for interview. However, for one of the smaller units no such transfers could be found. A change to the research protocol was made to permit us to approach patients who had been treated at the units for at least three years, on the grounds that they were aware of their right to move but had (implicitly at least) exercised a positive choice to stay.

The research process was not purely inductive. Rather, broad areas of questions were pursued to test the working hypothesis that underlies the government's patient choice policy, namely that the freedom of patients to move – patient choice – might have had an effect on the way the units delivered services. If more consumer choice (and funding that supports those choices) creates more responsive services, then one might expect the interviewees to report the following:

- a proportion of patients willing to switch units for quality reasons
- a desire to attract new patients and keep patients
- a sense of what patients want in addition to quality clinical care
- action to align services with what patients are perceived to like.

This last point, action to improve services, could be undertaken to attract and retain as many patients as possible. But providers might also change their behaviour in the light of losing patients not because of a desire to have as many patients as possible, but from a professional desire to provide a good service, prompted by the negative signals sent from departing patients.

Staff were asked the following broad questions:

- Did they think patients knew of their right to switch, if so, how many switch and for what reasons?
- Did staff perceive some patients were more mobile than others?
- What sort of services did they provide and were they different from other NHS specialist areas in any way?
- Why did staff think the services had developed the way they had?
- Did staff worry if patients switched away from their unit?
- If so, how did they find out or understand why patients switched, and did they then design services with this in mind?
- Was there any ‘competition’ for patients, and if so, what effects did this have?
- What other factors might have contributed to any changes in providers’ behaviour and services?

For patients the questions were as follows:

- Were patients aware of their right to move?
- If they had moved, for what reasons did they do so?
- If they had stayed, why?
- What did they value about their provider of choice?
- What sort of information did they use and where did they access information?

Interviews were transcribed, coded anonymously and analysed. In addition, anonymous national data for 2003 were released from the Survey of Prevalent HIV Infections Diagnosed (SOPHID) by the Health Protection Agency’s Centre for Infections. SOPHID is an annual prevalence survey, which records patients with HIV/AIDS accessing HIV/AIDS services within a calendar year. The data can be used to compare units on the numbers of patients, their ethnicity, which health authority region they have travelled from, and probable means of exposure to the virus. Results from analysis from the SOPHID data are presented alongside the data from the interviews.

Ethical approval for the study was granted from the South West Multi-Centre Research Ethics Committee.

The findings

The findings from the staff interviews are presented first, followed by the findings from the interviews with patients.

Staff perceptions of patient switching

Who does it and why?

Most of the staff interviewed felt that most patients were aware they could go for treatment elsewhere. Some of those interviewed, particularly at the two small outer London trusts, thought that patients might not be aware at the time of diagnosis, and that they were not routinely told so. But nearly all staff thought that, over time, patients tended to become aware of their rights, particularly if they came into contact with support groups in the voluntary sector. Several staff at the larger centres thought that gay men in particular tended to be more aware of their right to move, usually because of the networks of communication existing for that group.

> *I'm sure the majority know they've got a right to move; they come here initially at least and at most other units in London, they come in as part of the STD service and it's made very clear to them that they can go into any STD service, and I'm sure that even if they didn't know when they first come here I'm sure they find out very quickly either through talking to each other or talking to the community organisations.*
> (Lead clinician, Trust A)

All interviewees thought that on the whole few patients actually switched between units, although most were reluctant to quantify the scale of movement.

> *I'd say there was a core group of patients, probably less than 10 per cent, who do move around, and some will go to more than one centre at the same time.*
> (Lead consultant, Trust E)

> *We see three or four a year in day care who've moved.*
> (Lead nurse, day care unit, Trust D)

SCALE OF MOVING

Some staff thought that the scale of movement had varied in the past, but there was little consensus about the timing. Two thought that movement had been greater in the early 1990s, before the introduction of antiretroviral drug therapy, when patients were seeking out the latest clinical trials. Another thought that the first wave of HIV, in the 1980s, had seen a decline in the mobility of gay men traditionally associated with the STD clinics (when it had been a 'daily occurrence', as patients sought out any care they could find), but that movement had increased after the introduction of antiretrovirals, as patients were healthier and better able to move.

REASONS FOR MOVING

The logic behind the current policy to expand patient choice is that patients would move to access care that better satisfies their needs, perhaps on grounds of convenience or because of the desire for better quality treatment and care. Staff were asked to describe the reasons why patients had moved to or from their units. Three broad reasons were identified:

- **Confidentiality** This was described as a powerful factor driving patient behaviour. Many staff identified the patient's desire to keep their HIV status hidden from their families, community or GP as a reason for moving. This tended to mean the patient switched fairly quickly after diagnosis to access care that was some distance from their home, in order to reduce the possibility of chance encounters with family or friends in the hospital, or the possibility of their identity being revealed in some other way.

  There's stigma, people don't want their GPs to know because GPs are family doctors and due to confidentiality they don't want other family members to know so they go as far as possible.
  (Counsellor, Trust A)

- **Geographical constraints** Staff mentioned that one obvious reason for people switching was because they moved house, or in a few cases because they worked nearer another unit. Another reason mentioned was the dispersal of asylum seekers to other parts of the country. A third reason was the tendency, mentioned mostly in connection with gay men, of a change in personal relationships prompting a switch, either to follow a new partner or to avoid an ex-partner.

- **Search for better quality** Most staff reported that they had come across patients who did switch units in the search for better-quality care. Staff described patients moving to access a wider range of treatments, which includes the search for specific treatments available only at certain centres (such as Nu-fill, a treatment to correct the facial wasting side-effects of some of the drugs) or to access new drugs on clinical trial.

  Non-clinical aspects of quality were also frequently mentioned, in particular the characteristics of staff – especially consultants – were perceived to be a quality issue and patients were described as looking for doctors who were friendly, or, conversely, avoiding doctors with whom they had had a personality clash. Staff also mentioned that some patients switched in order to stay with a doctor who had moved to another unit.

  Several interviewees mentioned a tendency among some patients to assume that their local services, particularly those outside London, would be of a poorer quality. Some reported patients who were willing to travel considerable distances to avoid using their local services.

  As it stands now I have patients who come from Edinburgh, Blackpool, Derby, Bristol, Wales, Cardiff, the South, Brighton, even though there are services in those places that are probably quite adequate. But patients will travel, they don't mind. They perceive a better service in a better place, they will try and access that service.
  (Doctor, Trust C)

> Continuity of staff contact, particularly with consultants, was considered to be an important issue for patients. Many staff thought that patients valued highly regular contact with the same, named doctor.
>
> *Patients complain if they see a different doctor every time, that makes them change.*
> (Doctor, Trust E)

ARE SOME PATIENTS MORE MOBILE THAN OTHERS?

Staff were also asked whether they could generalise about the patients who tended to move and the consequences of such movement. Many felt that patients were not equally well informed or equally inclined to travel. Some staff noted differences in switching behaviour according to patients' ethnicity or sexual orientation.

> *It's perilous [to generalise] but my impression would be you're more likely to encounter that [movement] more among the white gay men than among the African men and women.*
> (Lead consultant, Trust E)
>
> *Minorities, refugees are different… they have less information. Gay men know exactly what trials are on, know about their illness, are aware of other hospitals. Other groups leave everything in your hands – 'you advise me' – and are less willing to find out.*
> (Consultant, Trust E)

Others felt that education was the deciding factor, and that patients from Sub-Saharan African backgrounds tended to be well educated (although not usually well-off) and were perfectly capable of searching out the best care.

> *Many of the Africans as well have come from educated backgrounds and are resourceful to have got themselves to the UK, sometimes without their families. They are upwardly mobile like so many first-generation immigrants, they are well-informed individuals and try to get the best treatment.*
> (Lead consultant, Trust C)

Those units serving a predominantly non-white population observed that on the whole their patient cohort was unlikely to switch. This view was typical.

> *The freedom to switch, it's not an issue here… they are not a sophisticated group of patients.*
> (Nurse, Trust A)

Staff perceptions of HIV service quality

If the choice–responsiveness hypothesis is correct, then one would expect to see a higher quality of services for HIV delivered (because patient choice was acting as a lever), compared to similar services where patient choice was lacking. A key question to staff was about their perceptions of the services offered by HIV units compared to other parts of the NHS, and whether choice had driven those differences.

Staff were asked to describe the nature and quality of the services they delivered and to compare them with other parts of the NHS they deemed appropriate. Many staff drew comparisons with specialties such as oncology or renal and dialysis units, where patients were often in contact with the service for long periods. Staff were also asked to explain what in their view constituted ‘quality’.

Range of services

All staff described services that were designed to respond to social as well as medical needs. All had specialised outpatient clinics to monitor and treat the virus directly, with appointment systems designed to limit waiting to between 15 and 30 minutes (patients interviewed tended to validate this reported waiting time). Staff also reported that patients who presented without appointment were seen, but that this practice was discouraged. In addition, the following services were also described: counselling, psychiatry, complementary therapies (massage and aromatherapy), and access to legal and social services advice. Three of the trusts also had pharmacies in the HIV units. In four of the five trusts, waiting rooms were described as being different from other waiting areas, with free tea and coffee and internet access (and free Danish pastries in one case).

Four of the five trusts studied had their own inpatient units: rooms were private, with their own bathrooms. Two units had their own chefs on the ward, and staff described how patients could get food cooked on demand. Another trust said patients were offered a choice of ‘African freezer meals’. Staff described the physical environment as being different from other parts of the hospital, with wooden floors, wooden doors, and more pictures on the walls.

Quality of services

Many staff were of the opinion that the services they provided were not typical of the wider NHS. When asked to explain this, many described the need to address patients’ wider social problems in order to deliver effective treatment.

> *I am quite clear that the service we offer here is envied by all my other colleagues in the hospital. They would dearly love to be able to have what we have… and I feel that we’re offering a good service, we’re offering a holistic service, we’re offering what the patients actually want. Although my agenda as a physician is purely to keep the patient healthy I’m very much in keeping with the opinion that unless you actually offer a holistic service and are able to deal with their [the patient’s] agenda, you’re much more likely to fail.*
> (Lead consultant, Trust A)
>
> *I actually think we run a better standard of care, so for example if a patient of mine complains they are feeling a bit depressed or something, I might be able to send him to a psychiatrist quicker than if a diabetic patient in another part of the hospital came up with that clinical presentation.*
> (Senior clinician, Trust C)

Many staff talked about a system to make access to care by patients easier, either through keeping waiting times short or by allowing patients to turn up without an appointment.

> *A lot more easy access. I’ve got a chronic condition myself and I know I couldn’t simply turn up to my provider unannounced, I’d be told I had an appointment in six weeks’ time*

> *if I was lucky. I think its really easy access here. We won't turn anyone away… maybe we'll see them initially and say come back on such or such a day and see the doctor, but we'll always see them.*
> (Nurse, Trust A)

Sometimes, even when service quality was defined more in clinical terms, the human qualities of staff were always mentioned in their perceptions of what patients valued.

> *First, informed advice, expertise, diagnosis, putting them on the right treatment. We've done outcomes research here and we are the best anywhere. We give patients very detailed patient information sheets, containing our outcomes data. Second, we offer the best research for patients, and third, patients want to see nice people, who are kind.*
> (Lead clinician consultant, Trust C)

> *All the surveys that have ever been done, all the things that you or I might consider important, best care and things, they [the patients] don't regard that as important at all, its actually all whether the doctor's nice to you or how long you wait in the queue.*
> (Senior consultant, Trust D)

Staff also referred to the physical environment as being different.

> *There are wooden floors, it's not clinical, it's a home from home. It was built at a time when there was no therapy, so it was a hospice setting not a medical setting. We're called the palace by the rest of the hospital. Patients who have to go to other bits of the hospital get a bit of a shock… They say its awful, they don't listen, they don't know you, they don't get any attention. We do pamper them.*
> (Senior nurse, Trust B)

Staff perceptions of factors driving up the quality of services

Many of those interviewed perceived the quality of the services they delivered to be different from those in other parts of the NHS, and in many cases superior. It is beyond the scope of this study to establish to what extent these subjective perceptions have some objective reality. Nevertheless, a key assumption underlying the reasons for introducing patient choice now is that providers will react to the signals patients implicitly send as a result of the choices they make. Patients taking their custom elsewhere, it is argued, should prompt providers to examine why patients are switching away and to respond to this loss of business by addressing the reasons for switching. To investigate this assumption in the context of HIV units, interviewees were asked to set out a range of reasons why they thought services had developed in they way they had. They were then asked whether patients' ability to vote with their feet had played a role in the shaping of services, and if so, how significant it was.

Why did services develop in the way they did?

As might be expected, staff reported a number of factors that they perceived to have contributed to the development of HIV services, which did not generally include the threat of patients moving unit. This may not be surprising, as although HIV services certainly accommodated the right of patients to switch, this was not a specific or necessarily high profile aspect of services.

Nearly all the staff interviewed would begin their explanations of service development by describing the desire to respond to the specific needs of HIV patients. A common theme was that HIV had only comparatively recently become controllable (antiretrovirals became available in 1996), and prior to that there were few options for those who became ill, which led many to describe the holistic quality of the services as essentially 'palliative' in nature.

> *Patients were dying in the beginning. We could do nothing. All you could do was help them die with dignity.*
> (Consultant, Trust D)

This led to a desire to offer services aimed at improving the patient's sense of well-being as much as responding to physical needs. Several of the nursing staff also felt that, as a result, the role of nurses had a much higher priority among clinicians. Many staff also felt they had been moved to perform in a special way because of the lethal nature of the illness coupled with the stigma experienced by many patients in other parts of the NHS.

> *It was a disease that came out of nowhere, it was a disease that was associated with a lot of fear, a lot of prejudice, and many health care providers would turn their back on it, but others decided we want to get involved with this because of these issues of stigma.*
> (Lead consultant, Trust E)

Coupled with this was ring-fenced funding, which before the advent of antiretrovirals (and hence higher drug bills) in 1996 was referred to as 'generous'. One member of staff referred to funding as being the deciding factor.

> *A lot of it just comes down to funding, and traditionally HIV has been well funded or feeding on the funding we had in previous years. I think that most clinicians, certainly most clinicians I speak to in this hospital, would quite happily, given the funding, offer the same level of service.*
> (Consultant, Trust A)

Many senior staff also noted their relative freedom and autonomy from hospital management and, crucially, having control over their own budgets.

> *It's not only the level of funding but the autonomy as well, because this department is very much more autonomous in its funding than any other department… I know how much money goes in and I know how much money goes out, and I'm able to negotiate with our finance officers on that basis and am able to make strategic choices based on that, whereas a lot of my colleagues are just put into a generic system, like for instance they see their patients in a generic outpatient department over which they have no control.*
> (Consultant, Trust A)

Senior staff described a sense of having more freedom to innovate and try out new ideas.

> *In the early days we had an unbelievable freedom from bureaucracy. For instance, no GPs were trained, so we said 'we need to train them and can you give us the money?' 'Of course we can give you the money.' The whole ability of the system responded to what was seen as a massive impending catastrophe. And the degree of innovation was startling. We developed new algorithms of care on the hoof.*
> (Lead consultant, Trust D)

All staff were asked about the significance (or otherwise) of patient choice in their work. On the whole nursing and other staff did not think it was significant. Only one doctor talked about a time when he felt under pressure to retain patients.

> *I can remember seven, eight years ago, if a patient transferred to another unit you would get bollocked from a dizzy height – how dare you, what did you do wrong, why did that patient transfer? I mean all hell broke loose, what were you doing wrong that meant the patient was unhappy?*
> (Senior doctor, Trust C)

Another nurse could remember a time in the 1990s when her senior colleagues were concerned about patient numbers.

> *Every need and whim of the patient had to be catered for while we were building up our services… We've had such low numbers, often the consultants worried they would go somewhere else.*
> (Clinical nurse specialist, Trust B)
>
> *I still have a sense of abject failure if a patient leaves – that we could have done better.*
> (Doctor, Trust E)

On the whole these were minority views. Most non-consultant grade staff were neutral about the prospect of someone leaving, both in the past and particularly in the present climate, when HIV cases are steadily increasing.

> *We're not looking for patients… when someone wants to go, we're sad to lose them, but we'll survive.*
> (Clinical nurse specialist, Trust A)
>
> *I think there's that thing in the back of your mind that they can vote with their feet, but I think in a sense the comfort for everyone, and we all know this, is that we'll never be short of work.*
> (Doctor, Trust E)

However, a very different picture emerged from the lead consultants in all the trusts, who were well aware of the movement of patients as a key additional driver in the shaping of their services. All the lead clinicians interviewed, particularly those directly involved in establishing units, mentioned the connection between building up the numbers of patients and the funding that followed.

> *You need to build your patient cohort up, and with those patients comes money which enables you to build up your service and create a nice environment to work in and to offer to the patients. So that's definitely part of it.*
> (Lead consultant, Trust A)
>
> *We were, you know, like a business enterprise. We were developing a new HIV unit, which if the number of patients didn't increase then there would have been unequivocal good reasons to close the unit and, you know, that's it and one can't argue with that.*
> (Lead consultant, Trust B)
>
> *We could bid if we could show we had the patients, they brought the money, a bit like payment by results, except you were playing catch-up. But basically it was about building up patient numbers.*
> (Lead clinician, Trust C)

> *Because of the way AIDS was ring fenced and funded from an early stage, it allowed people to understand the better the service they provided for the patients, the more patients they'd have, the more money they would have, and you know that there was a positive circle attached to that.*
> (Lead clinician, Trust D)

Being aware of the importance of patient numbers is only half of the equation, however. The critical question was whether the need to attract and retain patients had resulted in changed behaviour on the part of service providers. This in turn depends on the perceptions of the growth in those patient numbers: did the clinicians in charge of the unit feel that a stream of patients was inevitable, or did they take action to make sure that patients chose their unit? The picture drawn by interviewees was that for much of the 1990s patient numbers were rising, but not quickly enough to avoid taking action.

If they took action, what form did it take? Responding to the choice incentive could include taking action to improve quality, taking action to ensure a supply of patients (demand), competition with other units (or contestability – behaving as if in a competitive environment) for patients, and gaming around the incentives, for instance 'cream-skimming' to maximise income.

Choice: did it lead to a different emphasis in services?

Most interviewees took the view that, professionally, all staff wanted to deliver the best clinical treatment, but several examples were given of the need to pay more attention to a range of non-clinical issues, judged by staff to be important to patients.

> *Yeah I think [choice affected] all sorts of things, I think the care, the attention we pay to the physical environment certainly is due to that, we are conscious of that feeling if you were to walk in here as a patient would you want to stay here? It's the same approach with our receptionists, we're all aware that people can just decide to disappear and we need to make sure at all stages that if people are dissatisfied we try and deal with that.*
> (Lead clinician, Trust E)

> *We'd done our own [patient] survey so we got a pharmacist in very early because they were complaining much more about the wait for the pharmacy than they were for us; we had our own kitchens installed, in the inpatient ward, to produce food when the patients wanted it – one of the things about HIV is that they've got a much better appetite for food in the morning, so they would all be cooked an enormous breakfast and all the meals were cooked on the premises in a simple arrangement that wasn't too expensive, and people ate when they wanted to eat. We were very sensitive to what the patient wanted, so we were the first to start an information exchange and we had a whole series of computers where patients could look up what they wanted on the internet, a whole host of innovations did largely come about because we were keen to keep the patient population and to make it grow.*
> (Lead clinician, Trust D)

Other examples of services driven by the desire to attract patients include the ordering of drugs in advance by a unit that could not provide an in-house pharmacy of its own, improving the physical environment (for example adding wooden flooring, armchairs, and free tea and coffee), running clinics at weekends or evenings to improve access, and running specialist clinics to appeal to specific groups, for example women, who might need crèche facilities. Some of these facilities were provided by the NHS, some in co-operation with voluntary groups.

Some interviewees also mentioned that the selection of staff was influenced by the need to create attractive services.

> *My motto was 'the patient is king', and it ran through everything we did, I was looking for clinicians, nurses – whoever joined the service we would recruit people who really cared about patients. We had to offer a better service.*
> (Lead clinician, Trust C)

Choice: obtaining information about patient preferences

The actual movement of patients between units sends only the very crudest of signals to providers about their services. Of importance to units were the reasons for switching and the reasons that patients might have for considering switching. Interviewees were therefore asked how they found out from patients what a 'better' service might look like. Most responded that the main method was by talking to individual patients and listening to any complaints that arose. A common theme was that HIV patients tended to spend considerable amounts of time with their consultants (and other professionals) on a fairly regular basis, leading to a sense of confidence on the part of providers about what they might or might not like. Nevertheless, most units also reported that they had tried patient forums and surveys, usually independently of any central initiatives from the trust. There was a recognition among some clinicians that no method was foolproof, and that often those patients with the loudest voices tended to dominate.

> *It's very difficult in reality to find out what patients really want. Open meetings are poorly attended; focus groups are better as people are specifically invited. But the problem with all these things is that it's the activists that come, so the average patient, the average Ugandan lady with three kids, wants very different things from the average gay man who's on the internet all day long, and so to actually make sure you're achieving what you need for everybody is very difficult.*
> (Consultant, Trust D)

Responding to patients on an individual basis could also lead to similar biases, according to one doctor.

> *I think that we probably get a biased view. Because in any clinic, if you're seeing 20 patients and you see two people who complain and demand things, those would be the two that you remembered and ruined your day, whereas the eighteen who were lovely and kind and respectful and grateful would be forgotten in a flash. So I think they are probably over-represented in our minds.*
> (Doctor, Trust C)

Choice: managing demand

HIV units were operating in an environment where GP referrals played (and still play) a minimal role, unlike most other hospital specialties. Many of the clinicians spoke about taking action during the 1990s to make sure that patients were initially treated at the units.

This involved, for example, building relationships with smaller district general hospitals and small STI clinics, which could then refer newly diagnosed patients. In two cases it also meant developing 'same-day testing' clinics to attract patients. One consultant also talked about accessing patients admitted to the trust via other routes in the early days.

> *If a patient came into casualty, I got them [A&E] to phone me at home and I would always come in. I got all the most difficult patients, people who lived close by but were being treated somewhere else. They'd come in for emergency treatment and I'd look after them and then they'd stay here.*
> (Consultant, Trust C)

Consultants at the two smaller units also spoke about activities to get their unit known in the locality, which included giving talks to community groups.

> *Taking every opportunity to go and speak at voluntary-sector groups to make ourselves known within the African community, and Africans live in communities and it's a very important thing and they speak to each other, they know each other within the community.*
> (Lead consultant, Trust B)

Choice: competition and contestability between units

If patient choice was acting as an additional incentive on providers, then the hypothesis would predict a sense of competition between units, or at least a sense of contestability (the sense that the potential of patient movement is powerful enough to change behaviour).

Several of the interviewees talked about a competitive atmosphere between units. For example, if one unit delivered a service, others became aware of it and felt pressured to emulate this development. A consultant at one of the two smaller units saw the choice of services they provided as being influenced by those on offer at the larger units, driven by the possibility that patients might otherwise switch.

> *A typical large HIV unit would offer legal advice, or access to legal advice; social service advice, and you'd often get the social worker in-house; complementary therapies were very popular and common, so aromatherapy and massage; support by community groups based within the clinic. Those things were started by the larger units and the smaller units felt, or saw, that that was a good thing and therefore emulated that as well and so we realised that unless you offered that sort of range of services as well, patients would go to the larger units because it was available there and perhaps not at the smaller units.*
> (Lead clinician, Trust A)

One interesting finding was a perception that HIV services were operating, if not in a fully competitive environment, at least in one that was contestable. Although some staff were aware that in practice patients did not move very often, it was the prospect that they might that influenced staff.

> *If a GP had referred a patient to us, we could say to them 'this is the treatment we've decided to give you for cost reasons and we're going to give you this, you don't have any choice'. But we can't do that because we know that if we prescribe the cheapest*

> *drug, which may be just as effective, our patients will always go down the road and get the once-a-day kind of drugs they want – the once-a-day drugs are the current fashion. So although patients don't do that, I think it's that awareness that they might that affects us.*
> (Lead consultant, Trust E)

Patient choice: fear of exit?

While patient choice and the ability of patients 'to take their business elsewhere' implies an incentive on providers to respond to the choices patients make, in practice incentives are only effective if they chime with the motivations of providers: a trust that does not care how many patients it treats or attracts will not respond to the signals patients send as a result of their choices. In this respect therefore, staff were asked about why they wanted to see their units grow larger. Some explained that a 'critical mass' of patients was needed in order to take part in clinical trials, whereas others saw it as a means of obtaining more money to fund experiments in new types of services.

Some staff perceived the desire to be the biggest and best as no different from the professional rivalry that exists in other specialties, but tempered by the networks of doctors who had trained together or been colleagues before moving to other units. What appears to have been different from other parts of the NHS was that some of the interviewees believed that their units might disappear altogether if they could not keep their patient numbers up. Several consultants mentioned a period of overt hostility between the units during the 1990s that was now considered to be over. In one case it was directly linked to a threat of reorganisation of units within several neighbouring large trusts.

> *In that period people here [in the trust] were wanting to see that the activity was increasing commensurable with the investment, and there was talk about rationalising HIV inpatient services, even I mean merging with other [units] but it never came to pass. But that was a very acquisitive period, all HIV units were aware of it.*
> (Lead clinician, Trust B)

This led to perceptions that the larger units in particular were overly critical of the quality of care in smaller units, and that co-operation was damaged as a result.

> *It's quite clear that the bigger units were fairly aggressively acquisitive about patients, and one constantly heard stories about how consultants at some of the bigger units were openly saying that the patients should not go to the smaller units because they'd get a second-class treatment.*
> (Lead consultant, Trust A)

> *Historically we were under threat from Trust [X], so the politics between the powers that be in our unit and the powers that be in the other unit have always been muddied, and I have always thought it very sad, because we're all in it together.*
> (Consultant, Trust C)

Choice: gaming or cream-skimming?

Competition for patients might in theory be linked to behaviour to maximise income through 'gaming', for example looking for patients who would be less costly to treat.

Early funding for HIV treatment was linked to AIDS cases (the term for the many conditions that might affect a patient as a result of the virus). Because this form of funding pertained for most of the 1990s, during the so-called 'acquisitive' period, interviewees did not report any attempts to look for relatively healthy (less expensive) rather than more seriously ill (and more costly) cases: the money was designed for the sick. However, from 2000/01 the payment system has changed to cover diagnoses of HIV rather than cases of AIDS (in the light of more effective drugs and a decline in the mortality rate). One consultant mentioned that this did create a disincentive to treat the sickest patients.

> *One of the issues with the current funding arrangements is there's a tremendous temptation to shuffle off the most complex cases because they are a total loss leader: you get paid more or less from the number of patients that you see, rather than the case mix, so in the old days you got paid for the illest patients, so you were keen to treat the illest patients, so it was a positive incentive.*
> (Lead consultant, Trust D)

Another consultant referred to gaming by some of the trusts in order to secure funding. Trusts were paid for patients who had most recently been seen (because patients moved around). One example given was of smaller trusts sending patients on a shared-care basis to a larger trust (who had more specialist services) only to find that the larger trust had claimed the full year's payment for the patient.

> *It was in the accounting process. I seem to remember the census date for saying how many patients were under their care was the last day of a six-month period. So you were allocated that patient as being your patient if their attendance was closest to that final day. It was alleged that this larger unit was registering all their patients as having attended on the final day of the six months, even though they might have been seen at the smaller unit much closer to the end of that period. But because of the way they were registered the money went to the larger unit.*
> (Consultant, Trust A)

Choice: specialising, or responding to a niche market?

A general feature of supplier behaviour in a competitive environment is to avoid direct competition (and its associated costs) through, for example, specialising to serve a niche market. Some of the lead clinicians interviewed did report that they had intended to respond to a particular group, but it was not always clear that it was motivated purely by a desire to carve out an uncontested share of the market.

> *Being a woman, I wanted to look after the very small number of HIV-positive women at the time. I started a separate clinic for women, designed to be a one-stop shop where you could see a psychiatrist, get a smear, see a counsellor, social worker, midwife, links to paediatrics; clinics were held between 10 and 3 to fit in with school time, and we built a play area and so on.*
> (Lead clinician, Trust C)

However, the benefit of having specialised in this way appears to have paid dividends for the trust in question.

> *Over the years large numbers of African females have moved to see us because we are perceived to have a very good woman's service. Through the network and their friends*

> *they all decide that they want to come and see me, and so I have queues of African ladies all sitting outside; they even bring me food, as they say I'm too thin – potatoes and fish from the market and that, so they do.*
> (Doctor, Trust C)

What is clear from the SOPHID data is a marked difference in the demographics of patients at different trusts, whether classified by ethnic group (*see* Fig 3, opposite) or by mode of transmission (which identifies patients by how they acquired the virus, by 'sex between men' or via heterosexual sex, for instance (*see* Fig 4, opposite)).

The senior clinicians at the trusts with larger proportions of gay male patients did not report that they had deliberately aimed their services in any way at that group rather than others. By contrast, the lead clinicians at the two smaller trusts, with predominantly black African heterosexual patients, were conscious of responding to that group rather than the gay men.

> *I couldn't provide a similar environment to the other units. We were smaller and we didn't have as many gay staff as other units… I suppose the other units were an environment where gay men could feel more comfortable, and here we have a largely non-gay men group. I felt it wasn't a problem because I couldn't see how I could recreate that environment. Our model is African and I didn't see how we could go both ways. You have to have a critical number of people to create a certain kind of service.*
> (Senior consultant, Trust A)

Another put it more bluntly.

> *If we get scene gay men here, young gay men, they wouldn't stay here. They'd transfer their care, because they don't want to go and sit in a waiting room full of Africans.*
> (Lead consultant, Trust B)

Perhaps another reflection of this is the extent of travel to the two larger units, as noted in Table 1. The two trusts, D and E, with higher proportions of white gay men also have much higher proportions of patients who travel from outside their own locality to access treatment. In fact, in the case of Trust D, virtually every strategic health authority (SHA) in England is represented in their patient cohort.

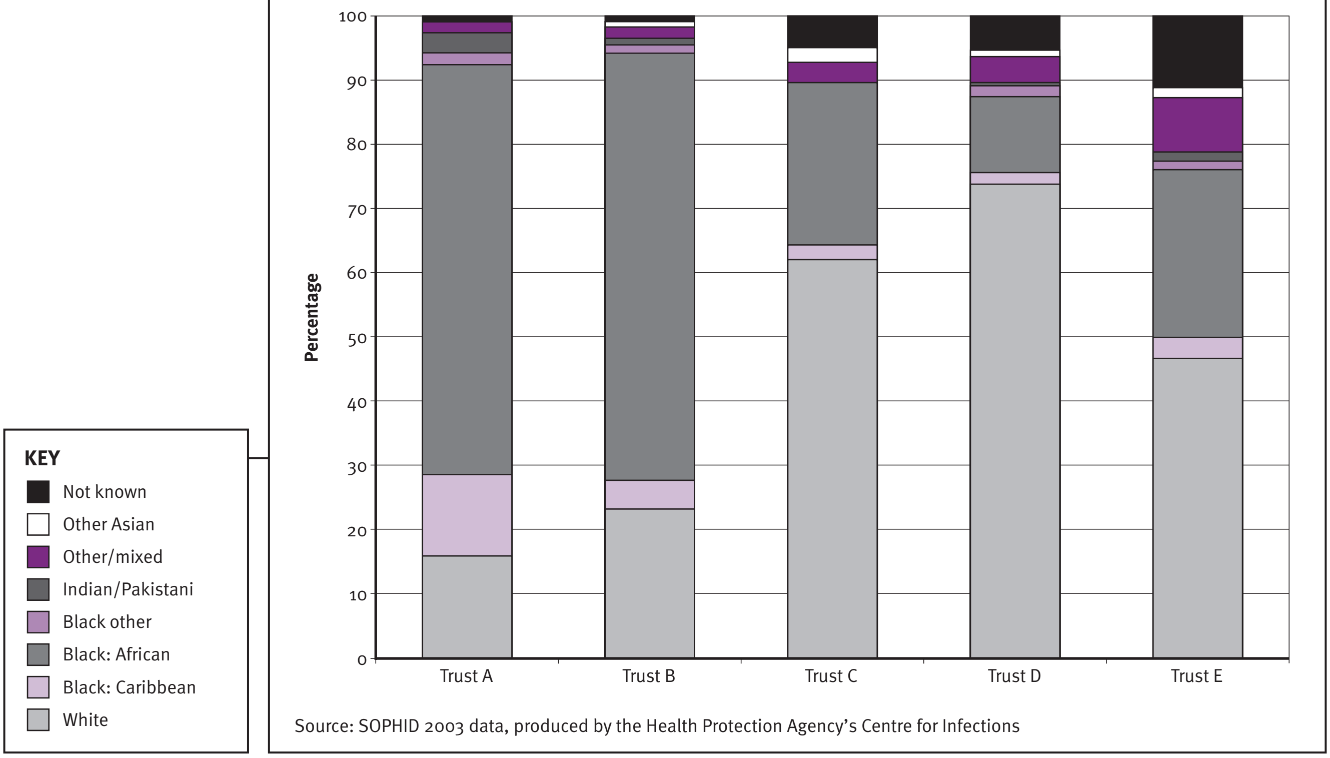
TABLE 1: EXTENT OF PATIENT TRAVEL TO SPECIFIC UNITS BY SHA

Name of trust	Number of SHAs from where patients are travelling	Proportion of patients seen from outside local SHA (%)
Trust A	6	2
Trust D	32	56
Trust E	30	54

Choice: information and expectations

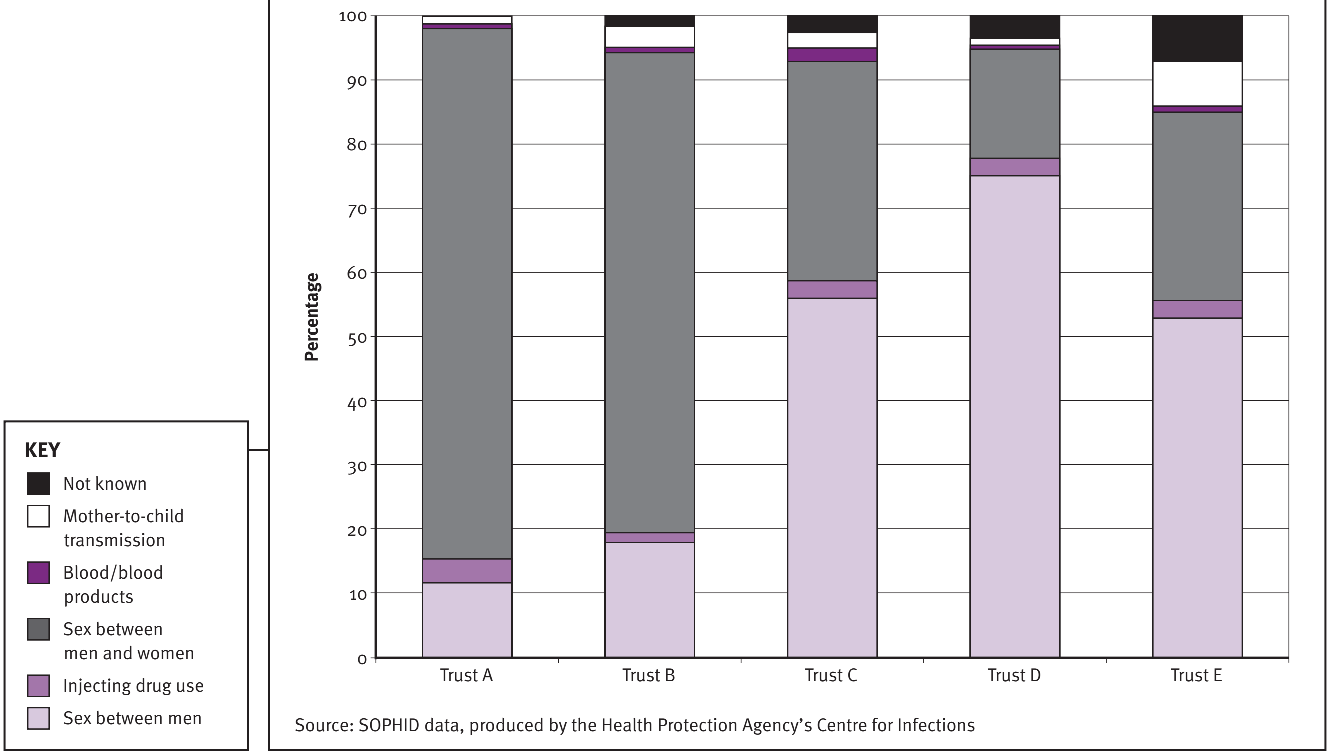
A key aspect affecting the efficiency of choice-driven markets in allocating resources is information about services on offer. HIV/AIDS is a sector that has had an unusual level of information available to patients, pioneered by the voluntary sector from the 1980s

3 ETHNIC CATEGORIES OF PATIENTS AS PROPORTIONS OF THE WHOLE PATIENT COHORT AT FIVE TRUSTS, 2003



Source: SOPHID 2003 data, produced by the Health Protection Agency's Centre for Infections

4 CATEGORIES OF PATIENTS BY ROUTE OF TRANSMISSION AS A PROPORTION OF THE WHOLE PATIENT COHORT, FIVE TRUSTS, 2003



Source: SOPHID data, produced by the Health Protection Agency's Centre for Infections onwards. All staff interviewed were happy about the level of information available to patients, even if it challenged their own knowledge at times.

> *Patients were very well informed of their problems, and this was exceptionally motivating for clinicians. If you have a patient who asks you about a drug, you look silly if you don't know, there was a huge pressure to keep up to date… it's a stimulating atmosphere to work with well-informed patients.*
> (Lead clinician, Trust C)

However, there was a recognition that 'well informed' could sometimes become 'over-demanding'. In retrospect some staff felt that the competitive atmosphere had led them to provide too much for patients.

> *It went too far in the beginning. There was this perception that unless you offered exactly what the patients wanted they would go elsewhere: every unit felt they had to offer a service where a patient could just turn up and say 'I am HIV positive, and therefore I want to be seen', even if they had an ingrowing toenail or a runny nose.*
> (Lead consultant, Trust A)

Staff in all units mentioned the move to scale back the GP-style services they had once offered, which originated from the time when the stigma of HIV was extremely high and many patients refused to go to a GP. Many units now encourage patients to see a GP. However, despite this scaling-back, many staff spoke of a minority of patients who were still considered 'demanding', that is, still wanting instant access to the consultant, and not just in person.

> *Patients' expectations are unrealistic, very consumerist. Their email has to be answered immediately.*
> (Senior consultant, Trust D)

> *I worked in a clinic where the doctors were even more accessible than here, and I didn't think that was terribly healthy because the patients were very, very short tempered and were making demands and having tantrums, and if I ever had to see them [for counselling] they didn't want to wait for more than about two minutes or they'd get really stroppy.*
> (Staff member, Trust A)

Some lead consultants spoke about the difficulties of tackling high patient expectations as they attempted to rationalise services, because the status of HIV has changed from an almost universally lethal condition to a chronic but serious one with a good life expectancy.

> *They [the patients] have high expectations now. But we are trying to be ahead of the game and saying [to patients] that you don't need to see your doctor every time but you can be seen by a team, to break up this cult of personality around the doctor.*
> (Senior consultant, Trust D)

Patients

The original research plan had been to interview five patients at each of the five trusts (25 in total) who were known to have switched their care from another unit to the current one, and to explore their reasons for moving and their sources of information. However, it became apparent that the two smaller trusts treated very few patients from outside their immediate strategic health authority area, and staff were unable to find patients who fitted the other criteria (having transferred, but also well enough and willing to talk confidentially about their HIV status). So, instead, patients were selected who had been attending the units for at least three years and questions were asked about their reasons for staying with current unit, their sources of information about services, and their knowledge about other units.

Reasons for accessing units

The majority of patients in the two smaller trusts, A and B reported that they attended the units because they were in hospitals close to where they lived. Some had had their HIV tests there; others were referred by local clinics after their tests.

> *I have been brought up here, I have used this hospital throughout my life, I lived in the area throughout my life.*
> (Patient, Trust A)

A few mentioned that they did have a hospital closer to home, but travelled for reasons of confidentiality.

> *I didn't like the hospital nearby because at that time HIV disease – people take wrongness about this business – so I don't wanted my society to neglect me about this thing, that's why I didn't want to choose the hospital which is nearby me.*
> (Patient, Trust A)

One was referred by a community nurse when his health deteriorated rapidly under the care of a local hospital. Looking for better-quality care was much more commonly cited by patients attending the larger three trusts, C, D and E. Two patients had been referred by district general hospitals when they developed problems with drugs, but on the whole most patients had found out by themselves where they wanted to go and referred themselves, because they judged the quality of care in their old unit to be worse than that of the new one.

Some patients referred to the reputation of their unit as a 'centre of excellence', or that they wanted to access clinical trials or specialist treatments available only at that centre. Some also mentioned that personal qualities of care-givers at their original units had been lacking.

> *Things were starting to creak a bit, it was obvious to old hands that decisions were being taken on the basis of saving money and the receptionists were no longer friendly, just chatting amongst themselves.*
> (Patient, Trust C)

Awareness of right to move

Whether they had switched units or not, all patients were asked about whether they were aware they could move and, if so, how they had found out about this. The majority were aware of this right, but a few at the smaller units were not. Most were not informed by the hospital or clinic staff at the outset, but found out later from a variety of sources, from friends, support groups, social workers and community nurses.

> *My social worker told me, yeah, and there is one hospital in the city somewhere, I don't know where exactly, I don't remember the name, the social worker has told me that we can send you there if you don't like it here.*
> (Patient, Trust A)

Perceptions of quality

All interviewees were asked about what 'good quality' meant to them. A common theme in the answers to this question was the attention paid to them as an individual, in terms of both the access they were given to doctors and also the manner in which the staff dealt with them.

> *The doctors can remember who you are and your problems. My old doctor who only saw 31 patients couldn't remember my details when he saw me. Also the nurses [here] understand your fears but don't pity you. I like the speed also, your bloods are back in no time and you don't have to wait.*
> (Patient, Trust B)
>
> *I can see same doctor each time, that's good because you don't have to start all over again each time; feels more social here, more relaxed, always have a coffee, chatting, it's nice, it's not like a hospital waiting room, it's rare to wait more than 15 minutes.*
> (Patient, Trust D)

A few were in a position to compare their treatment in the HIV unit with that in other parts of the hospital. Two patients had been treated as outpatients in other departments of the same hospital and noticed a marked difference.

> *I was treated with chemotherapy for breast cancer. It was old and dirty and terrible. They had too many patients to look after and I felt really alone. It's much warmer in the HIV clinic, they treat you as a person, they try to look after your soul as well.*
> (Patient, Trust A)
>
> *In all the [other] places I've been too, it's a bit grim, ripped seats held together with gaffer tape. But here it's done out nicely, pot plants and things, even plasma screens for the HIV patients.*
> (Patient, Trust E)

Patients at the larger trusts were more likely to refer to their liking of 'clinical' quality – in other words, being given the best drugs and follow-up care. In the absence of comparable outcomes data (there are no publicly available mortality data or other kinds of outcome data) patients tended to refer to the existence of clinical trials and the publishing reputation of their doctors as proxies for clinical quality.

> *It's good to be on a drug trial, not least because you get much better quality care, you're not just left sitting there.*
> (Patient, Trust C)
>
> *The doctor is on the ball, knows his stuff, listens to you. But there's also new facilities here and it's a wealthy area, so I thought these would be advantages. I do read the HIV literature and I can see that my clinician is at the forefront of developments, and obviously feeling better is the proof of the pudding, the gold standard.*
> (Patient, Trust D)

Some patients (all gay men) also referred to the social makeup of the clinic as being important.

> *I like this clinic because it's big and gay friendly.*
> (Patient, Trust C)

> *It's a huge issue for me to find a dedicated gay clinic. Here they have a women's day, which is typical of clinics for African women. It's not a separatist thing, but if I could find a dedicated gay clinic I would go to one.*
> (Patient, Trust C)

Other patients welcomed the variety they'd found in the units and were less concerned about being amongst people like themselves.

> *I feel more comfortable here, there are ladies, children even, it's not just a gay thing, it feels better. If it's just gay men it can feel too narrow, too 'Lily Savage'*
> (Patient, Trust E)

Patients who had been treated at small clinics outside London reported the most marked differences in the quality of care, usually in terms of lack of HIV-specific clinical expertise of the doctor and poor nursing practice.

> *I used the internet a lot and read a lot, but sometimes I seemed to know more than the doctors.*
> (Patient, Trust D)

> *I was made to feel like a leper. My blood samples had a big label marked 'high risk'.*
> (Patient, Trust B)

Sources of information

Patients spoke about a wide variety of information sources and had a good deal of experience in using information. Patients used word of mouth, the internet, written information provided by units, and a host of specialist HIV publications. Some of the trusts also provided computers and internet access. At one extreme, a few patients were aware of information but not inclined to access it.

> *I think there is plenty of information out there. I have never looked for it but I mean in most of the waiting rooms there are various papers and there is plenty of groups that are around, none of which I've ever contacted or spoken to.*
> (Patient, Trust A)

> *I picked up a leaflet once about HIV. But I don't believe in patient dabbling.*
> (Patient, Trust C)

At the other extreme patients stated that they were highly informed, through both word of mouth and written sources.

> *There's a lot of word of mouth. You hear 'my clinic is excellent', you go along and see what it is like. There's quite a grapevine out there.*
> (Patient, Trust C)

> *In the past we were more informed than the doctors, finding out about treatments from our friends and contacts in the United States.*
> (Patient, Trust C)

Support groups played an important role in some cases.

> *My social worker suggested I move to Trust D, saying it would be better-quality care, and I also called a gay helpline and they were wonderful.*
> (Patient, Trust D)

Because of the small sample size it is not possible to reach any conclusions about whether some patients are more likely to access information or support than others, or whether there are any connections with the size of unit and willingness to use or access information.

Experience of the voluntary sector

Four patients interviewed were (or had been in the past) involved in the voluntary sector, with experience of two trusts, B and C. One had experience of the voluntary sector in the early days (1980s).

> *We had offices inside the hospital. It made a difference having us on the doorstep. If we heard of something going on inside the hospital, we went down to the ward to find out what was going on. There were appalling services in the early days and we were not prepared to put up with it – you can't talk to us in this way.*
> (Patient, Trust C)
>
> *People got angry with the way they were treated and it led to change.*
> (Patient, Trust C)

Another patient was also involved in a voluntary-sector group in a London borough, without a specialist HIV unit nearby. He had noticed a marked difference in attitudes between gay men and the newer patients from African backgrounds.

> *As soon as it became Africans, the importance went off the boil. They [Africans] don't have people on the streets demonstrating. African refugees are so disenfranchised, they are fearful of saying it's a crap service. People are grateful for getting something at all. We didn't accept that.*
> (Patient, Trust B)

The same patient also echoed a view expressed by the others that there was also a cohort effect among gay men. Just being gay did not guarantee activism, probably as a result of the better treatment now available.

> *Younger gay men are more complacent. They tend to think: 'we've got pills and we'll be ok'.*
> (Patient, Trust B)

One patient had experience of voluntary-sector activity aimed at people from African backgrounds. That patient's recollection was that the African groups tended to be more fragmented and coalesce along national lines, with differing degrees of openness about the virus.

> *We learned a lot from the gay men activists and we [Ugandans] were the first to share platforms with the gay groups. But I found that people from West Africa, like Congo, simply won't even talk about their illness or get involved in any kind of groups.*
> (Patient, Trust B)

Discussion

> *I think there's always been criticism of HIV because we're perceived to be 'haves' rather than 'have nots', we're perceived to have more money than others. But my view is: sod that, the NHS should be striving to be like us; if they are looking for a model of care, they should be looking to be like the HIV units. And patients have a role to play. Most patients aren't vocal enough. They need to start saying 'this is not good enough'.*
> (Doctor, Trust D)
>
> *There have been times when I've had to send my patients to a consultant outside the HIV unit and there have been times when those consultants have been off-hand with my patients. I've had to phone them and explain that if I behaved like that with my patients, I wouldn't have any patients.*
> (Consultant, Trust E)

This study aimed to explore the assumption that lies behind the government's current policy of extending patient choice, namely that by giving consumers freedom to choose and ensuring that providers are financially sensitive to those choices, more responsive and better quality services will be the result.

Did choice have any effect on HIV/AIDS services?

The study attempted to explore this hypothesis in a specialism (HIV/AIDS) that shares some of the features of the current patient choice policy by accident rather than design: namely the presence of free choice of treatment centre and a funding system which, per force, had to allow the funding to follow the decisions of patients.

The first challenge was to isolate the effect of choice from all the other factors that are likely to have influenced the delivery of HIV/AIDS services. The motivations of health care professionals in any field are likely to be multilayered, and in many ways the HIV/AIDS sector has features that make it exceptional, including the sudden onset of an initially lethal virus, the highly politicised nature of its early development, the youthfulness of those affected by the virus, the high level of state and voluntary-sector funding it received, the vociferous and persistent nature of patient lobby groups and so on.

The interviews with staff confirmed that patients *were* aware of right to move and some were willing and able to switch units that better suited their needs. The interviews with both staff and patients *also* confirmed that the services delivered in the units aimed to be responsive to patients' needs. There is no doubt from the accounts of the interviewees that the services at these units are different from those in many other parts of the NHS. The care offered to people with HIV includes services aimed at meeting non-clinical needs and an emphasis on ease of access unusual in the context of the rest of the NHS.

So is it reasonable, therefore, to conclude that patient choice was the key to this unusual 'responsiveness'? When asked why services took the shape they did, all staff referred to the special features of HIV/AIDS mentioned above and their concern to care for patients whom they felt were marginalised. Almost without exception, staff below the level of lead consultant rejected the idea that there had been any competition for patients or that patients' freedom to choose made any difference to their work. Nevertheless, it also became clear from the interviews with the senior staff that some aspects of their behaviour *were* affected by the competition and contestability inadvertently created by the policy of 'open access' and the funding system set up to support it. These interviewees appear to have been concerned about the potential departure of patients, and took steps to attract and retain them in a way that they themselves perceived to be different from other clinical specialties in the NHS.

In this study it was notable that there are no comparative clinical outcomes data available for public consumption, even though several units were publishing outcome data unilaterally. The extensive literature from the voluntary sector does not explicitly rank units for quality (although one website does equate larger size to better clinical outcomes). What are listed in patient directories are the range of therapies and services on offer. The working assumption of most of the patients interviewed was that the doctors were all going to deliver the right drugs, but what might vary was how nice they were, or what extra services might be available. Clinical quality is taken as a given for all but a tiny minority of those interviewed. This minority made decisions based on a quite sophisticated knowledge of drugs, including their cost, which was sometimes taken as a proxy for quality. Similarly, the interviews with the senior clinicians revealed that choice appears to have focused their minds on the additional services that might be popular with patients, such as complementary therapies, or differently timed clinics for easier access. The drive to deliver high clinical quality appears to have been independent of the competitive pressure generated by choice.

What factors enabled choice to operate in this instance?

What appears to have been a critical factor in the case of HIV is the immediacy of the incentives. Lead clinicians could see the money come directly back into their units, rather than staying at the level of the trust. This also appears to have been reinforced by a high degree of managerial autonomy. What also appears to have been an important incentive is fear of failure, with lead clinicians in some cases aware that their units might disappear if patient numbers were seen to be falling. Funding also appears to have been critical, particularly in the creation of a 'virtuous circle' whereby improved services generated extra patients, which generated more money. Capacity also mattered. The accounts of the providers interviewed paint a picture of a time in the 1990s when patient numbers were growing more slowly than in the past five years, which led to a sense that patients had to be attracted to and retained at the units. Since 2000 some sort of optimal provider/patient ratio appears to have been exceeded, which seems to have made the providers less concerned about patients voting with their feet because there are now perceived to be more than enough 'to go round'. In other words demand is perceived to exceed supply, indicating that providers may not have to try so hard. It is impossible to say yet whether this has led to a lower level of responsiveness toward patient needs.

Above all, the system worked because of the presence of a small group of well informed and assertive patients who were prepared to switch providers in search of better quality. One striking finding is that by all accounts the number of patients who bother to find out about alternative units and switch to them on the grounds of better quality (rather than simply convenience) is quite low as a proportion of total patient numbers. What is interesting is that the senior staff were clearly aware that not many patients switch in reality, and yet still felt that they had to attract and retain them: a singular example of contestability in action.

Freedom of patient movement appears to have created units that are very different in their demographic makeup. There can be no doubt from the accounts of staff and patients that some units are considered to be ‘gay friendly’ and that others are aiming at an African/non-gay patient group. Most staff appeared to accept this as a necessary consequence of stigma. Both groups still experience considerable levels of prejudice and are looking for a safe environment. However, a minority of interviewees expressed unease with the results of this, and felt that the NHS should provide an environment where all groups could feel at ease. On the other hand, the reality of some groups choosing to be treated elsewhere, does appear to have allowed some of the doctors to specialise, particularly in delivering care for patients from African backgrounds, many of whom also need high levels of social and emotional support.

Lessons for policy

There are of course some key differences between the case of HIV units and wider patient choice in the NHS as envisaged so far. Current choice policy is focused, initially, on elective (non-emergency) surgical procedures, short term in nature, whereas HIV is a long-term condition. In the case of HIV, many patients refer themselves and do not use their GP as a gatekeeper. Under the wider policy, patient choice will only be available in conjunction with a GP consultation. The funding system in the case of HIV was not specifically designed to function as an incentive (unlike Payment by Results (PbR)), but to reimburse providers faced with patients who were not necessarily being referred by local GPs or likely to come from the locality.

Despite these caveats, there are some interesting facets to the experiences of providers and patients in this study that lend support to both the proponents and the detractors of wider patient choice.

The architects of the current policy on patient choice have designed a system that, if it works correctly, gives providers an additional set of incentives – backed by financial rewards – to improve the services they offer to patients. Although the current NHS reforms to hospitals draw on incentive mechanisms traditionally associated with competition and markets, the new incentives are not meant to replace or usurp more traditional public-sector motivations, going with the grain of an ‘altruistic’ public sector (Le Grand 2003). This is particularly so in health: as Simon Stevens (one of the architects of the current reforms) puts it: ‘there is little alternative but to embrace “professional conscience”, not just contract or regulatory oversight’ (Stevens 2004). The accounts of the lead clinicians appear to back this up: if choice had an effect, it was to reinforce an underlying aim to deliver high quality care to people with HIV/AIDS.

The challenge for those implementing the current policies of choice and PbR, is to make the incentives a reality for those who actually deliver the services. The study found that lead clinicians enjoyed real control over their budgets and saw the direct benefits of good performance. Under the current reforms, good performance will be reflected at the level of the trust's balance sheet, but it could be reflected at the level of clinical sub-units, which would then tie in success more directly to the teams delivering care.

The ability of patients to refer themselves directly to the provider seems to have been a key element in sharpening these incentives. Senior staff felt that none of their non-HIV colleagues faced such a direct prospect of a patient walking in off the street, or a person walking out and admitting themselves to another unit. Would patients have been so keen to switch if it had entailed an automatic visit back to a GP to request a referral elsewhere? This kind of self-referral is not envisaged for the wider NHS, but given the experience of HIV it might be considered more widely for those with diagnosed long-term conditions.

A further question concerns how the incentives work *within* the units providing care, and cascade to all members of staff, including receptionists and nursing staff. Patients interviewed in the study were sensitive to the treatment they experienced from all staff, not just the doctors. Many of the patients spoke highly of the non-doctor grade staff, and yet this group do not, on the face of it, appear to have been affected by the 'choice mechanism' incentives spoken of by their senior colleagues. Nevertheless, it was clear that the senior staff were aware of the work delivered by all staff and the potential reaction of patients to those staff. Under the new reforms, the quality of clinical leadership within teams or units will be critical and thought needs to be given about what motivates the full range of staff with whom patients come into contact.

It is not yet known what impact greater freedom of choice will have on the NHS as a whole. The logic of greater choice is increased diversity of services, appealing differently to different groups. Indeed, choice has been heralded as a policy that could actually deliver better care for ethnic minorities, through specialisation, for example (Reid and Phillips 2004). However, the prospect of increased 'self-segregation' in other areas of social policy such as education, is beginning to cause some unease.

Perhaps the greatest concerns expressed about the wider choice policy have centred on the different abilities of individuals to make choices and their willingness to move. In the case of the HIV units studied it is clear that staff perceived some patients – typified as better educated and pushier – as being more mobile. The numerical data from the units clearly show that some units appear to have attracted certain kinds of patient who are prepared to travel quite long distances to access the unit of their choice. The key question is whether those who choose to move obtain a better standard of care than those who do not. In this study the staff at the two smaller units with less mobile patients appeared to be no less professionally driven or committed to deliver a high standard of care than those at the larger units. However, this is an impossible question to address with any objectivity, because of the absence of comparable clinical outcomes data (*see* above). Some of the staff at the larger units were insistent that the evidence they were familiar with showed that larger units delivered higher-quality care, which would bestow clear advantages on those able and willing to access their services. As patient choice rolls out across the NHS as a whole it is quite likely that only a small proportion of patients will choose to travel beyond their local hospital. A close watch will need to be kept both on the demographic makeup of those who travel and on the comparative performance of providers who are popular compared to those that do not attract many extra patients.

This raises a further question of whether ‘popularity’ will equate with high clinical quality and relates to the nature of the signal patients send to providers when they make a choice and the way providers interpret the meaning of the signal sent. What, in other words, informs or influences patients’ choices? It is not clear how far the government intends the consumer to act as a regulator of quality in the NHS in the future, or how much of an appetite patients will have to consume data on clinical quality. However, without such pressure generated by fully informed patients, the temptation on the part of providers might be to invest in ‘peripherals’, such as nice waiting rooms, possibly at the expense of clinical quality. In the case of HIV units, the generous funding in the past has reduced such dilemmas – patients could have expensive drugs as well as the aromatherapy – but the difficult decisions are now beginning as the funding gets tighter and the number of HIV cases increase.

Several lead consultants admitted that, on reflection, patient choice was an important contributory factor to what was widely acknowledged to be an ad hoc and poorly planned HIV service in London. Staff were aware that units are incentivised to grow and to hang on to their patients, but co-operative networks have been hard to establish. The ‘acquisitive’ phase of the mid to late 1990s, when competition was heightened by an exogenous threat of unit closure or merger, was also described as a low point in relations between trusts, particularly between smaller and larger trusts. A similar climate might well prevail for hospitals between 2006 and 2009 as the incentives created by PbR and choice begin to bite. The government has made clear its intention to allow institutions that are not popular with patients, to fail if necessary (Hewitt 2005a).

Competitive pressures can create innovation, but they can also act as a dead hand on reform. Several interviewees referred to an unwillingness to take risks and alter services for fear of losing patients. Allowing patients who vote with their feet to set the planning agenda poses a clear risk to the NHS, particularly for those patients who are unable or unwilling to move themselves.

Conclusion

The Labour government's reforms to the NHS, with their heavy emphasis on patient choice and consumer power, are designed to change the way patients are treated by the medical profession.

The accounts of patients and staff in the HIV units in this study show that it is possible to create services that aspire to put the needs of patients at the centre. Many of the factors that led to this are unique to HIV/AIDS. However, the freedom of patients to choose does appear to have had some impact. Patients' ability to vote with their feet added a key piece of leverage on units. Nevertheless, providers were already pretty well motivated to deliver a different style of care, faced with the lobbying of determined (and young) patient groups, equipped with more than adequate funding and commitment borne from the history and nature of illness with which they were dealing.

It may well be possible to generate similar levels of responsiveness through the current policies of choice and financial incentives. But the experience of HIV also exposes a risk that more consumer choice will damage equity, still one of the core objectives of the NHS. Not all patients exercise their right to move. Those that do are often more demanding and have louder voices than those who do not. The critical question for the NHS in the future is how to ensure that the actions of this minority drive improvements in those hospitals they have chosen to avoid.

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