

# Choice and Equity

PCT SURVEY

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# Introduction

One of the key objectives of the government's drive to increase patient choice in the NHS (in England) was to enhance equity (Department of Health 2003). When patient choice was rolled out in January 2005, primary care trusts (PCTs) were given responsibility for making sure that all patients had an equal *opportunity* to choose, by providing information and support to those who might otherwise struggle to exercise choice.

There may be other benefits, apart from greater equity, in giving patients the right to choose; however, as the government itself has set such store by this issue, it is important to establish whether or not the new policy is providing opportunities for all.

In November 2006, we conducted a survey of PCTs, asking them what action they had taken to ensure equity of choice. We found that, despite some examples of good practice, only a minority of PCTs had identified which groups might find making choices harder, only a minority had put in place concrete measures to 'support' choices for these patients, and a majority reported that ensuring equity is 'difficult or very difficult'. While it is too early to tell whether patient choice will deliver fairer *outcomes* for patients, this survey suggests that equalising the opportunity to choose is already proving challenging within the NHS. This finding has to be seen within the context that this survey was conducted during a period when PCTs were being reorganised and therefore distracted from many operational matters. There were also both technical and ideological difficulties with the IT system through which choice was being rolled out.

# Background

Since January 2005, under the policy of patient choice, patients needing a non-urgent hospital outpatient appointment should have been offered a choice of hospital by their GP. The 'menu' of possible choices was initially four or five mainly local providers, but the list has now been extended to include private sector treatment centres and foundation trusts nationally. The policy applies to nearly all the 9 million outpatient appointments offered within the NHS each year, with only a few exclusions (maternity and referrals under the two-week cancer target, for example). The policy has been accompanied by the introduction of an electronic booking system, known as 'Choose and Book', which has involved substantial reforms to IT systems at both GP and trust level, a process that is not yet complete and has had, in the government's own words, some 'challenges' (Hewitt 2006a). Choices should have been offered to patients even in areas where the electronic booking system is not yet in place.

The government plans to extend choice to cover all non-emergency referrals, and patients will have a choice of any hospital or treatment centre in the country by 2008 (Department of Health 2005).

The government has put forward three main objectives for increasing patient choice. First, choice has been justified on the grounds that it is essential to modernise the NHS and that surveys suggest that the public want more choices in public services, including health (Department of Health 2006a). Second, and perhaps more importantly, choice is designed to act as a lever to improve performance: by linking payment to the numbers of patients that hospitals treat, the government hopes that hospital providers will become more responsive to patients' needs in an effort to maintain and enhance their income: 'the intention is... to increase competition between providers' (Department of Health 2006b). According to the government, potential quality improvements that should result from enhanced choice include shorter waiting times (Department of Health 2004b) and, more recently, better 'clinical standards... canteens, car parks, crèches and cleanliness' (Hewitt 2006d).

Choice has a third objective – namely, increasing fairness or equity within health care. By extending choice to all patients (particularly the choice of a shorter wait), the government has argued it is correcting two forms of inequity: first, where the better-off could find shorter waiting times by paying

for treatment in the private sector (Department of Health 2000; Reid 2003; Hewitt 2006a, 2006b, 2006c, 2006d) and, second, where some patients could insist on choices (of shorter waits or better clinical quality) within the NHS, because of their better knowledge of the system (Reid 2003).

What we are doing, what Labour governments have always done, is making available to the many what the few have always had. (Hewitt 2006c)

The government has been keen to emphasise the results of surveys which show that people from lower income groups place an equal or greater value on choice than those in higher income groups (Department of Health 2006a; Hewitt 2006a). It has also been robust in the face of concerns that choice might make the NHS more inequitable (Farrington-Douglas and Allen 2005; Wood 2004).

... there is no evidence – as our critics claim – that it is the middle class who are the principal beneficiaries. We found with the pilot experiments on choice that the less well off took up the choices offered as frequently as the better off. (Hewitt 2006d)

The government set up a number of national pilots to test patient choice, which allowed patients waiting for surgery in a number of specialties the option of travelling to an alternative hospital to receive quicker treatment. The evidence from one of these pilot projects did indeed show that access to choice was equitable, with no inequalities 'in access to, or uptake of alternative hospitals by social class, educational attainment, income or ethnic group' (Coulter 2005). However, there were two important differences between the pilots and the current policy. In the pilots, all patients were eligible for free travel and all were entitled to help from a patient care adviser: neither is mandatory in the implementation of choice at the point of GP referral.

In making the claim that choice will increase equity in the NHS, the government also recognised that some people might find it harder to exercise choice:

... there needs to be sufficient support in terms of advice, decision making and towards transport and other considerations to make sure it is open to all. (Reid 2003)

The Department of Health has commissioned research and a set of guidelines for ensuring equity within patient choice to enable PCTs to identify needs and commission services from the voluntary and community sectors (Council of Ethnic Minority Voluntary Sector Organisations 2004). The full commissioning guidance on equity and choice has so far not been published by the Department of Health. More general guidance on patient choice, published in 2004, made clear that it was the responsibility of PCTs to identify those patients who might need support in making choices and, where necessary, to commission services from the voluntary sector, use specialist patient care advisers and meet the transport costs for patients eligible for the existing Hospital Travel Costs Scheme (Department of Health 2004a, 2004b). More recent guidance is available on the Choose and Book website under the heading 'Ensure patient choice and equity' (Choose and Book 2006), which also encourages PCTs to carry out needs assessments, and, where necessary, to take action to make sure that:

... there is targeted support available for patients who are likely to need additional help in making choices. For example, through Patient Care Advisers, community advocacy groups or voluntary sector organisations. (Choose and Book 2006)

There has as yet been no systematic evaluation of the impact of choice 'at the point of referral' on equity, although there is some (limited) evidence from the Department of Health's national patient choice survey that has been designed primarily for performance management rather than research purposes (2006c). The survey asked a sample of patients attending outpatient appointments whether they recalled being offered a choice by their GP (sufficient numbers of positive answers trigger an

incentive payment for GPs) and whether they were aware of the policy of patient choice in the first place (Department of Health 2006c). Information has been collected about the age, gender and ethnicity of 79,000 patients, but not about disability, language needs or other needs. The survey found that 30 per cent of all patients could recall being offered a choice, but only 25 per cent of black and minority ethnic patients could recall being offered it. The written survey is available only in English, however. There was no apparent bias in terms of age – in other words, very little variation between the ages of those reporting a choice (although there is no breakdown of the 'over 65' age group). Interestingly, older patients (65+) were *more* likely to be aware of choice than younger age groups.

# The study

For this study, we sent an electronic survey to all 152 PCTs in October 2006, addressed to trust chief executives. The survey asked a series of questions about:

- the numbers and grade of staff dedicated to patient choice
- the type and location of information provided to all patients
- whether needs assessments had taken place
- what extra support had been commissioned
- whether extra steps had been taken to advertise help with transport.

The survey also asked for qualitative comments on the type of support commissioned and the nature of any barriers encountered in delivering equitable choice.

#### **FINDINGS**

A total of 67 PCTs responded to the survey, giving a response rate of 44 per cent. This low response rate is perhaps a consequence of the reconfiguration of PCTs that was taking place at the time of the survey; this involved reducing the number of organisations from 303 to 152 and might have heightened the risk that, within the PCT, the survey might not have reached the right person or that the post might have been temporarily vacant. The survey was anonymous. Not all of the respondents answered all the questions.

#### Staff responsible for choice

Of the 67 responding PCTs, 15 per cent (10) reported that they had a lead manager solely responsible for patient choice. Most (85 per cent) employed a lead manager with responsibility for other functions, with commissioning the most commonly cited. There was a range in the size of staff teams devoted to choice, from 0.2 whole-time equivalents (WTEs) to 6.75 WTEs, with an average of just under two full-time posts.

#### Public awareness of choice

PCTs were asked how they had made the public aware of their right to choose. Among the 61 PCTs who answered this question, the most frequently cited method was placing leaflets in GP surgeries and other NHS premises. Sixty per cent of these PCTs (36) also reported using libraries, and a minority (14 PCTs, 23 per cent) also said they had mailed information direct to people's homes. A few PCTs reported using other methods, including mailing information to small businesses, retailers, banks and estate agents or staging displays at community events or in shopping centres.

#### Information offered to help patients make a choice

All the PCTs who responded to this question (60) reported using the 'Choosing Hospital' leaflet (100 per cent), while nearly all PCTs said that they also offered the online help from NHS.uk (85 per cent) and the national Choose and Book helpline (87 per cent). Over half of the PCTs relied on only these information aids for patients, but a minority (42 per cent) also used other methods. These included: staff available by telephone at the PCT (including referral management centres); online help via the

PCT website; eight trusts reported the use of specialist patient care advisers based either at the PCT or in GP surgeries; one PCT also reported using a DVD/video.

PCTs were asked who they felt was the main person who helped patients make choices at the point of referral. The majority (55 per cent) said it was the GP, with a minority reporting practice nurses (one PCT) or practice receptionists (nine PCTs). About one-third of PCTs reported that a mixture of people played a key role, including people from Patient Advice and Liaison Service (PALS) teams or, in one case, members of a bilingual health advocacy team.

#### Identifying those in need of further support

Over half of the 57 PCTs who answered this question (33 PCTs, 58 per cent) said that they had not conducted a needs assessment to identify those who might need support in making choices. Of the 42 per cent who said they had, there was a variety of approaches to 'needs assessment'. These ranged from one PCT which reported that it had identified vulnerable patients through a process of meetings with stakeholder groups, to other more informal methods that included 'agreeing a list of groups with the strategic health authority'. Among those identified as vulnerable, the elderly were mentioned by 11 PCTs; those with physical disabilities (especially sensory impairment) were identified by 10 PCTs; people with learning disabilities, by 8 PCTs; people with mental health problems, by 7 PCTs; minorities or people with language problems (including asylum seekers), by 12 PCTs; young people, by 3 PCTs; and people on benefits, travellers, homeless people and carers were identified once by different PCTs.

### Support available

Support from a Patient Advice and Liason Service team (PALS) was the most common form of help offered to patients, with 73 per cent of PCTs using this method. Just over half of respondents said that translation was available, either at the surgery or via the PCT. A third of PCTs (36 per cent) said they offered support in Braille or Typetalk and a further 41 per cent reported using patient care advisers to offer personal advice to patients. Among those reporting other types of help, 30 per cent cited making literature available in other languages; support mentioned by other PCTs included having put in place access to mental health advocacy, access to the learning disability team, a dedicated PCT advice line and patient choice drop-in sessions in some practices.

Two-thirds of PCTs said they had not commissioned any *new* services to support choice; of the third who said they had (20 PCTs or 30 per cent of the overall sample), most had used the NHS but a small minority (4 PCTs in total) said they had used the voluntary and community sector.

#### Transport

Two-thirds of PCTs said they had not advertised to patients that they might be entitled to financial help; a third said they did. Twelve PCTs (18 per cent) reported that they were aware of increased travel costs, possibly arising from choices to travel further, but most (the remainder) did not.

#### **EQUITY AND CHOICE: BARRIERS**

Two-thirds of the 67 PCTs felt that delivering equity of choice at the point of referral had been fairly difficult or difficult, with a small minority (7 per cent) finding it very difficult, while 10 (15 per cent) said they felt it was not difficult.

Just over 70 per cent of the sample contributed some qualitative comments about the barriers they had encountered. Many of these comments related to barriers to implementing patient choice in general, rather than ensuring equity specifically. The most commonly cited problem was engaging GPs with patient choice (26 PCTs). Sometimes this was because GPs were reported to be sceptical or hostile to the policy overall, for example:

Many GPs seem to have a philosophical aversion to patient choice and are reluctant to engage in an informed conversation with patients about it.

There is still some resistance amongst GPs (either disagree with principle or want to support local hospital and consultant colleagues etc) to offering choice, which means that not all patients will have the same level of access

PCTs reported that this underlying hostility to the policy was also compounded by;

- perceptions among GPs that choice meant longer consultations
- frustration with the enduring problems with IT
- delays experienced by PCTs in getting leaflets and other information to disseminate.

Several PCTs also said that they couldn't be sure that GPs were having a discussion with patients, even if there wasn't any underlying dislike for the policy.

There is a difficulty in actually monitoring if GPs are offering choice, issues with CAB [Choose and Book] haven't always been helpful. There are different levels of engagement across the PCT as we have a population of approx 440,000 which covers affluent areas to some of the most deprived wards in the country.

In general terms it's about how overtly choice is offered and whether or not patients actually perceive that they were offered a choice. We know that there is a variation between some GPs' assertion that choice was offered and the patients' perception of that offer being made.

Many PCTs also mentioned that IT problems had distracted effort from other issues such as equity.

The focus to date has been on rolling out booking (to DoH targets that we consistently fail to hit because of technical problems with hospital software). We have therefore focused very little energy on choice.

Other general constraints included difficulties in getting both professionals and patients to engage with the idea of choosing between hospitals, especially where there were only one or two local providers.

*Historically this PCT has a 1:1 relationship with the local provider (because of geographical location) therefore there is no culture of choice of provider.* 

We have two excellent hospitals on our patch and most patients choose to go to [them] and the attitude of patients to private hospitals in some parts of the patch is mistrustful... that may change.

Some comments did relate to equity in particular – for instance, the difficulties PCTs felt were encountered by non-English speakers.

*Language barrier and high illiteracy levels, so having leaflets translated into different languages has not been as successful as earlier thought.* 

*Language (English as a second language) and ensuring patients have the right amount of understanding to make an informed choice.* 

Being able to offer translation services for everyone is not straightforward. Explaining the process when using 'indirectly bookable' is also more complicated and some groups do not realise that they have to make a phone call.

One PCT also remarked that some of the official language lacked clarity even for English speakers.

Nationally defined wording on Appointment Request paperwork generated by CAB [Choose and Book] is difficult for patients to understand; www.nhs.uk information is also difficult.

The other main barrier reported by PCTs was the cost of transport for those choosing to go elsewhere.

[This area] is a peninsula and people are reluctant to travel. For example, the local ISTC (orthopaedic) is based in [X] and most people offered the choice would rather wait for the local hospital. Transport continues to be an issue in terms of difficulty in getting to places using public transport and cost for those who are not on benefits so not entitled to reclaim transport costs (one trip to [X] ISTC for two people costs around £22).

Patient transport meetings with the ambulance service and the local trust identified that there just isn't capacity to support out-of-area referrals without investment in more ambulances.

## Discussion

Assessing whether patient choice has increased or decreased equity is not a straightforward research task. There are at least three stages. First, it requires an understanding of whether all patients had an equal opportunity to choose in the first place: were all eligible patients offered a choice and given help to understand the information on offer (where appropriate)? Second, it needs an understanding of whether there are any differences (by age or socio-economic group) between those who make active choices or defer decisions to their GPs, followed by an understanding of any differences between those who choose to stay with their local hospital and those who choose to travel to an alternative (and exploration of why some travel and some do not). Third, a further level of analysis is also needed to see whether those who choose to travel could be seen to have received a better quality of care as a result, in other words, a superior outcome through having made a choice.

This research focused on the first of these stages, asking whether PCTs had put in place the mechanisms that might equalise the opportunity to choose. The findings of the survey suggest that many PCTs are struggling to deliver an equal opportunity to choose for their patients for a range of reasons. On the other hand, some PCTs do appear to have devoted some time and resources to ensuring that all patients are informed about choice and that some are supported to make choices, for instance, by employing patient care advisers – a role that had proved very popular and effective in the patient choice pilots (Coulter 2005). Further research is needed to investigate just how these interventions are being used and how effective they are.

Patient choice of hospital at the point of referral is a policy still in its early stages of implementation. Choice has been introduced at a time of great change within the NHS. PCTs have been faced with considerable challenges in getting the computerised booking system to work and have also been reorganised themselves. Latest official figures suggest that less than a third of referrals are being made through the electronic booking system; however, this does not preclude a choice having been made even if the booking was made manually (Department of Health 2006d). There has been no official evaluation of whether flows of patients between hospitals have changed; this is the subject of forthcoming work at the King's Fund.

As patient choice becomes a part of routine care in the NHS in England, it will be interesting to see how much time and resources PCTs devote to ensuring equity of choice. Hospitals have an incentive to attract patients (through Payment by Results) and GPs have also been offered a financial incentive to adopt Choose and Book (at a cost of £50 million, according to the British Medical Association (BMA 2006)). But the incentives for PCTs to ensure equity of choice are less clear. Investment in patient care advisers (or other kinds of personal health advocates) to facilitate choice are unlikely to lead to any direct improvements in health status or to improve access to health care services. A review of inequities in access to health care suggests that those from poorer backgrounds are less likely to visit their GP in the first place, and, when they do, are less likely to get a referral for procedures such as hip replacements (Dixon *et al* 2003). Patient choice is not a policy designed to correct underlying inequities in referral rates or to boost access to primary care. It may be that those PCTs concerned about these wider inequities may decide that they cannot afford to divert resources to ensure equity of choice. On the other hand, lack of investment in equalising the opportunity to choose may open up a new frontier of inequity within the NHS, the dimensions of which are currently unknown.

## References

British Medical Association (2006). 'Focus on... Choice and Booking DES' [online]. Available at: www.bma.org.uk/ap.nsf/Content/focusCandB (accessed on 25 January 2007).

Council of Ethnic Minority Voluntary Sector Organisations (2004). 'College of Health: Choice and Social Exclusion Unit 2004' [online]. Available at: www.cemvo.org.uk/website/index.asp?Page\_Id=4 (accessed on 30 January 2007).

Choose and Book (date unknown). 'Provide patient information and support' [online]. Available at: www.chooseandbook.nhs.uk/staff/implementation/toolkit/choice/patient (accessed on 25 January 2007).

Coulter A (2005). *Patients' Experience of Choosing Where to Undergo Medical Treatment: Evaluation of London Patient Choice Scheme*. Oxford: Picker Institute Europe.

Department of Health (2006a). *Choice Matters: Increasing choice improves patients' experiences* [online]. Available at: www.dh.gov.uk/assetRoot/04/13/55/42/04135542.pdf (accessed on 25 January 2007).

Department of Health (2006b). *The NHS in England: The operating framework for 2006/7* [online]. Available at: www.dh.gov.uk/assetRoot/04/12/73/15/04127315.pdf (accessed on 6 February 2007).

Department of Health (2006c). *Report of the National Patient Choice Survey, May/June 2006, England* [online]. Available at:

www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsStatistics/PublicationsStatisticsA rticle/fs/en?CONTENT\_ID=4140523&chk=LcKJxp (accessed on 25 January 2007).

Department of Health (2006d). 'Minister announces one millionth choose and book referral'. Press release 14 October 2006. Available at:

www.gnn.gov.uk/environment/fullDetail.asp?ReleaseID=235989&NewsAreaID=2&NavigatedFromDepa rtment=False (accessed on 25 January 2007).

Department of Health (2005). *Health Reform in England: Update and next steps* [online]. Available at: www.dh.gov.uk/assetRoot/04/12/47/27/04124727.pdf (accessed on 25 January 2007).

Department of Health (2004a). 'Choose & Book' – Patient's Choice of Hospital and Booked Appointment: Policy framework for choice and booking at the point of referral. London: Department of Health.

Department of Health (2004b). *NHS Improvement Plan: Putting people at the heart of public services*. London: The Stationery Office.

Department of Health (2003). *Building on the Best: Choice, responsiveness and equity in the NHS*. Cm 6079. London: The Stationery Office. Available at: www.dh.gov.uk/assetRoot/04/07/52/93/04075293.pdf (accessed on 6 February 2007).

Department of Health (2000). *The NHS Plan: A plan for investment, a plan for reform*. Cm 4818-I. London: The Stationery Office.

Dixon A, Le Grand J, Henderson J, Murray R, Poteliakhoff E (2003). *Is the NHS equitable? A review of the evidence*. LSE Health and Social Care Discussion Paper Number 11. London: London School of Economics.

Farrington-Douglas J, Allen J (2005). *Equitable Choices for Health*. London: Institute for Public Policy Research.

Hewitt P (2006a). 'Reform is the only route to safeguard the NHS'. Speech at Braunstone Health Centre, Leicester, 17 March 2006. Available at:

www.dh.gov.uk/NewsHome/Speeches/SpeechesList/SpeechesArticle/fs/en?CONTENT\_ID=4131925&c hk=AiCFz8 (accessed on 25 January 2007).

Hewitt P (2006b). Speech to UK Public Health Association (UKPHA), 14 March 2006. Available at: www.dh.gov.uk/NewsHome/Speeches/SpeechesList/SpeechesArticle/fs/en?CONTENT\_ID=4131926&c hk=mv/jTM (accessed on 25 January 2007).

Hewitt P (2006c). Speech to GMB Public Service Workers Conference, Nottingham, 28 February 2006. Available at:

www.dh.gov.uk/NewsHome/Speeches/SpeechesList/SpeechesArticle/fs/en?CONTENT\_ID=4131105&c hk=HhdNII (accessed 25 January 2007).

Hewitt P (2006d). Speech to NHS Confederation seminar on 'Creating a Patient-led NHS: The next steps forward', 10 January 2006. Available at:

www.dh.gov.uk/NewsHome/Speeches/SpeechesList/SpeechesArticle/fs/en?CONTENT\_ID=4126499& chk=KTwhjQ (accessed on 25 January 2007).

Reid J (2003). Speech to the NHS Confederation Annual Conference, Glasgow, 26 June 2003. Available at:

www.dh.gov.uk/NewsHome/Speeches/SpeechesList/SpeechesArticle/fs/en?CONTENT\_ID=4031858&c hk=N/BAIs (accessed on 25 January 2007).

Wood C (ed) (2004). *Supporting Choice: Supporting vulnerable service users in making choices*. Report of the Social Market Foundation Seminar, 12 October 2004. London: Social Market Foundation.