Briefing*Paper*



Can choice for all improve health for all? The evidence on whether NHS patients can and should become consumers of health care

This briefing paper outlines the main findings of a review to assess the extent and nature of the evidence available on patient choice and its impact on equity, efficiency and quality within the NHS. It was commissioned in 2004 by the NHS Service Delivery and Organisation (SDO) Research and Development Programme and carried out by researchers at Manchester and Cardiff Universities.

Key messages

- Patients want to be treated as consumers of health care. They want better information about treatment options and to be more involved in making the decision as to which option to follow.
- How far patients behave as consumers depends on the severity of their illness, the nature of the procedure involved and their individual circumstances. Most severely ill patients face complex treatment options and prefer decisions to be made on their behalf by a well-informed and trusted health professional.
- Evidence that patients want the opportunity to select a distant hospital for non-urgent surgery is limited to situations where patients face a

long wait for a local hospital appointment and where there is a history of poor service.

- Wealthy and educated populations will be the main beneficiaries of a policy of extending patient choice, unless specific measures are introduced to help disadvantaged groups interpret and make use of information about health care (e.g. league tables).
- There is no evidence that giving patients greater choice will, in itself, improve the quality of their care. Some studies suggest that increasing choice may result in a deterioration in the quality and cost-effectiveness of services.





Background

Practical findings



The citizen as consumer is central to New Labour's approach to modernising public services. For NHS patients, this should mean:

- a more effective and efficient health system that is able to respond to individual patient needs
- greater equity as a result of extending choice beyond the affluent and articulate
- greater opportunity for patients to take responsibility for, and thereby improve, individual health.

The consumer organisation *Which?* hailed the option of choosing between five hospitals for non-urgent surgery as 'the jewel in the crown of the Government's patient choice policy'. Its success is widely seen as heralding an expansion of choice within the NHS.

However, there is evidence that a 'choice' policy may have adverse or, at least, unpredictable consequences. Choices about health care are significantly different from other consumer choices. Patients do not choose to fall ill or decide when they become sick. Their knowledge about the quality and effectiveness of the services they are going to use is inevitably imperfect: not least because their ability to make use of such information at a time of stress and vulnerability is likely to be compromised.

The efficiency of the NHS, moreover, affects those who do not use it as well as those who do. There is some evidence that a significant extension of patient choice may be impossible within existing resources and within the free-at-the-point-of-service system. Above all, there is a question mark over claims that the policy will improve equity of access to health care.

1. Do patients want choice?

Surveys show that, in theory at least, people welcome the chance to choose between health practitioners and treatments, especially when they face poor services and long waiting times. However, while members of the general public rate choice as important, as patients they are more equivocal. Evidence from systems that share similar features with the NHS suggests that there is relatively little enthusiasm among patients in other countries to take up choice of provider (Council for Public Health and Health Care, 2004).

As patients, most people prefer to have access to one good GP and hospital rather than several of indeterminate quality. They prefer to collaborate in decision-making with a trusted practitioner rather than take responsibility for making the decision themselves. They are more likely to rely on tips from friends and family than use published information such as hospital league tables or performance data, whether by hospital or individual clinician (Mennemeyer, 1997; Marshall, 2000).

These preferences become stronger when patients face a complex procedure (Fotaki, 1999), where there is more than one possible outcome or a life-threatening illness (Luker, 1995), and where a trusting relationship with the medical team is likely to be seen as of paramount importance. Thus, the opportunity to make a choice is more likely to be taken up in ophthalmology and other non-urgent surgery than in gynaecology or general surgery (Dawson, 2004). There is also evidence that people's ability to assimilate complex technical and scientific information that is required in order to take decisions independently, deteriorates at a time of stress and vulnerability.

Information about care options is certainly valued by patients but for other purposes than making independent choices: as a means of empowerment to take better care of themselves, to make predictions for the future even if this involves bad news, and to assess the expertise of their doctor (Henman, 2002). Along with these psychological benefits, informed patients are also more likely to comply with a treatment programme (Finlayson, 2001; Fallowfield, 1994).

Research also suggests that doctors need to be more sensitive to the extent to which individual patients wish to become involved in health choices and how information and advice on their illness can be most usefully presented to them. Doctors may need to acquire skills to distinguish between patients who wish to delegate and those who wish to share in decisionmaking (Beaver, 1996; Guadagnoli, 1998; Hamann, 2004).

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In sickness and in health

"A sick person is qualitatively different from a well person, physically, emotionally and cognitively. At a time when they are physically unwell and overwhelmed with anxiety, many patients appear to sanction a degree of paternalism if the relationship between their doctor and themselves is satisfactory."

Cassell E. 2003. Autonomy and Paternalism in Medicine. *Medical Journal of Australia* 159(11–12): 797–802.

"59 percent of patients versus 36 percent of non-patient public would prefer to leave treatment decision making to their doctors."

Degner and Sloan. 1992. Decision making during serious illness: What role do patients really want to play? *Journal of Clinical Epidemiology* 45(9): 941–50.

2. What limits patient choice?

Making choices is not just about ticking boxes. Several personal and individual factors have been found to influence the way patients make choices about their health. These include:

'Doctor knows best'

As the gatekeeper of secondary care, the GP makes the final decision as to whether patients require a specialist referral, and is likely to guide any choice they may be able to make. The Government, via the National Institute for Health and Clinical Excellence (NICE), also plays a role in framing the choices which patients are offered. Patients may abdicate health care choices further because they:

- don't know that they can play an active role in decision-making
- have a 'doctor knows best' attitude
- wish to avoid regret or responsibility for possible failure of the chosen treatment
- are reluctant to acknowledge the uncertainties of health care.

Lack of information

Most patients believe that they are given too little information about treatment options to be able to exercise choice effectively. Assessments of patient leaflets support this view with evidence that in a range of specialties, information given to patients is of poor quality, out of date and inappropriate (Coulter, 1998; Markham, 2003). Further, both GPs and patients overestimate the extent to which doctors share with, and elicit patients' opinions about medication, including risks and benefits (Markoul, 1995).

Patients' beliefs

Patients are individuals who bring their own beliefs, values and everyday experiences to the consultation – all of which can limit their ability to make choices. These include: their attitude to risk and their view of the medical profession (Howell-White, 1997); the extent of their knowledge of the illness or the relevant medical procedures (Marteau, 2001); their past experiences including experiences of discrimination (Klassen, 2002).

3. What helps people make effective choices?

There is no one-size-fits-all approach to helping patients to become informed users of health services. A range of strategies is needed to overcome barriers of race, language and education. The following are evidence-based strategies to support patient choice.

Good communication between doctor and patient

Informed choice requires an understanding of probable outcomes and the risks involved. This is largely dependent on the ability of the doctor to communicate clearly in a time-limited consultation (Green, 2003; Ford, 2003). Many patients do not receive adequate information from health professionals (Entwistle, 1998). At the extreme, some elderly people with arthritis decline the offer of hip surgery because they are unaware that they have a treatable condition.

Patient involvement in producing useful information

Patients' beliefs play a significant role in their ability to make an informed choice. Patients who decline the offer of a heart transplant are less likely to be aware of successful transplant surgery and more likely to have heard of people who have died during surgery or had an unsuccessful transplant (Hudak, 2002). The involvement of patients in the production of health education information should allow these beliefs to be identified and taken into account – thereby contributing to better informed choices being made (Entwistle, 1998; Gordon, 2001).

Good quality leaflets

Evidence-based health care is accepted as the basis of good clinical practice. Evidence-based patient choice may be equally important though it is unlikely to involve the same data, presented in the same way. Studies show that leaflets summarising evidence on decisions that women face in pregnancy and childbirth help to improve their ability to make an informed choice, although not all research supports these findings (O'Cathain, 2002). Consistent provision of this type of leaflet should bring about modest improvements in a patient's ability to make an informed choice.

Coaching

Training patients to take an active role in a consultation and to improve their ability to gather information has been shown to double their effectiveness in eliciting information from their doctors. Patients with diabetes are able to improve their blood sugar control following coaching (Greenfield, 1998).

Decision aids/interactive health communication applications (IHCAs)

This recent innovation aims to support patients in making difficult decisions about their health care. Decision aids are normally online, interactive support systems that provide both the research evidence underpinning the therapies available, as well as balanced information on the advantages and disadvantages of therapeutic choices. There is evidence that patients find decision support technologies supportive in confronting uncertainty and in addressing their personal values in relation to the scientific evidence available. Patients are also more able to reach a decision that is not prejudiced by individual values or educational background (Elwyn, 2006). Decision aids were developed to be supplementary to the doctor-patient consultation. Around 500 have been produced over the last ten years by both commercial and academic organisations. Where they have access to them, patients like them. However, they are not widely implemented or promoted by health professionals and services (Kravitz, 2001; O'Connor, 2004).

"Sometimes no-one knows whether it is best to have a test or not. Patients often don't realise that there is a lot of uncertainty in medicine and believe that every question about testing has a clear answer."

Thus <u>www.prosdex.org.uk</u>, an interactive health communication application (IHCA), produced by a group at Cardiff University, describes the background to a decision about whether or not to take a PSA test for prostate cancer. The aim is to help the patient understand the major health consequences that rest on the decision while also helping him to understand that there is no right or wrong decision to make. The evidence suggests that having the support of an IHCA enables patients to feel more confident about the choice they make which can have important beneficial consequences on outcome.

4. Does extending patient choice improve the health care system?

The introduction of consumer choice, and thereby competition in public services is widely considered to be a driver for increasing efficiency, equity and quality. However, evidence from the UK and abroad suggests that the impact of a 'choice' policy in health care is unpredictable.

Efficiency

Quasi-markets were introduced in a number of European countries in the 1990s by governments that wished to maintain the public sector but were convinced of the superior capacity of market-like incentives to deliver cost-effective and efficient services. An NHS quasi-market, giving health authorities and GPs powers to purchase secondary care services on behalf of their patients, was hailed as a successful experiment in widening choice in the NHS.

However, there is no evidence that it has either improved patient choice (Fotaki, 1999) or resulted in significant reductions in management or prescription costs or the use of expensive specialist services. Further, a decision to introduce managed care in the USA in the 1980s has reduced costs in some areas, while also reducing patient choice. The introduction of the National Institute for Health and Clinical Excellence (NICE) in the UK, designed to restrict patients' (and doctors') choice of available treatments to those that can be shown to be cost-effective, has been highly effective in reducing patient choice – both for newly licensed medications and popular but unproven alternative therapies.

Equity

There is substantial evidence that despite a 'free-at-thepoint-of-service' health care system, socio-economic status significantly affects both access to NHS health care and the outcome of episodes of illness (Dixon, 2003). There are claims that increased patient choice will reduce inequity of access, and therefore outcome, for instance, by reducing waiting times: while everyone might not take advantage of the offer of choice between providers, waiting times should improve for those who take up the offer of choice as well as for those who do not. Wealthy people may be encouraged by such a move to opt back into NHS care: thereby increasing social solidarity and reducing the risk of the NHS becoming a safety net service for the poor.

However, evidence from the USA suggests that vulnerable patients, including those from black and other minority ethnic groups are increasingly excluded as a result of extending choice (Klassen, 2002). An increase in inequity seems inevitable unless the choice policy includes a means of targeting disadvantaged groups, including older people, those who are less educated, those on low incomes and ethnic minority groups, to prevent such exclusion (Health Link, 2004; *Which*?, 2005).

Quality

Researchers who monitored the impact of quasimarkets (i.e. choice by GPs and health authorities) on the quality of care during the 1990s, reported that any improvements (largely as a result of reduced waiting times for non-urgent surgery) were short-lived. However, more recent research has suggested that quality may actually have deteriorated as a result of these reforms. A recent analysis of previously unavailable data sets found the introduction of a quasimarket in the NHS triggered an increase in mortality following heart attacks (Propper, 2004).

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Future research

5. Lessons to be learned from other public sectors?

Primary and secondary education

Educational reforms introduced in the UK in the early 1980s, aimed at improving equal access to a good local authority education, have persistently failed disadvantaged groups and schools in disadvantaged areas (Bell, 2003). Targeted voucher systems, intended to eradicate 'cream-skimming' (the educational equivalent of selecting low-risk patients in health care) have not been particularly effective either in England or elsewhere (Ladd, 2002). Parents with higher socioeconomic status remain more likely to get their child into their school of choice while poorer parents are more likely to select their local school (Burgess, 2005).

Implications for the NHS

In many ways, choice in health is different from choice in education. Yet the evidence suggests that higher socio-economic status confers an advantage in choicerelated policies in public services generally. It also suggests that as with education, a 'choice' policy might encourage 'cream-skimming' in the selection of patients: for instance, causing disadvantage to those with chronic illness.

Social care: direct payments and choosing a care home

The introduction of quasi-markets in social care in Sweden and the UK has not increased choice, quality or efficiency. Instead, the available evidence suggests they have produced:

- less diversity in the type of services provided
- increased provision by private sector
- increased responsiveness only for 'strong' clients
- an increase in public expenditure
- a decline in public trust.

Implications for the NHS

Social care provides some idea of how services for people with chronic illness might be affected adversely by a 'choice' policy. Choosing a residential care home is similar in some ways to choosing a hospital under the NHS *Choose and Book* policy. Comparative data suggests that:

- patients will be influenced by their own experience of the hospital and the experiences of friends and acquaintances, particularly regarding appearance and staff attitudes
- GPs will continue to have substantial influence over the choices that patients make
- historical patterns of local hospital use are likely to continue.

Key areas of research in order of importance

Impact of choice on equity

The literature on the equity implications of policies to expand patient choice is sparse. What research exists has largely failed to look at the characteristics of patients who were excluded or excluded themselves from the opportunity to choose.

Any expansion of patient choice should first be evaluated in terms of its impact on equity: both in terms of offering equality of treatment for equal conditions and in its contribution to combating existing inequalities in access and health outcomes.

Variation in the needs of individual patients or groups of patients

A small but important body of research suggests that there are significant variations in:

- the kind of choices that different individuals and different groups of patients wish to make
- the level at which they wish to participate in such choices
- the kind of support and resources that they need to make an informed choice.

Further research to identify the factors influencing these different choices and the value and meaning attached to choice by different groups and individuals should be seen as a priority. Such study is needed, not only to underpin a policy of choice in health care, but also to empower relatively disadvantaged groups of patients to collaborate in decision-making, a development which has been shown to improve health outcomes.

Other topics

Research is also needed to:

- find ways of identifying and preventing the development of perverse incentives that would disadvantage groups of patients, particularly the chronically ill
- monitor whether, and in what situations, a choice policy actually leads to more patient choice and what initiatives and conditions facilitate it
- find ways of managing patients' choice of ineffective or inefficient but highly popular treatments such as complementary therapies.

About the *study*

The process of the scoping exercise was built around a literature review, expert panel workshops and the knowledge of team members. An initial review of the literature focused on different theories of choice and consulted key experts to build an analytical framework.

The review of the literature was synthesised around three key indicators – efficiency, equity and quality – that were addressed for health care in the UK (separating primary and secondary care where appropriate), health care in other countries, and experience from social care, residential care and education. Choice of health services (e.g. choice of hospital) and choice of treatment in the individual doctor–patient encounter was looked at separately.

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The full report, this briefing paper and details of current SDO research in the field can be downloaded at <u>www.sdo.lshtm.ac.uk</u>

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About the SDO Programme

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