

PUBLIC VIEWS ON CHOICES IN HEALTH AND HEALTH CARE

A qualitative study

Rebecca Rosen, Natasha Curry, Dominique Florin

Extending patient choice is central to the government's reform of the NHS. Patients will be offered a choice of hospitals for planned operations from December 2005 and will soon be offered choice in other areas of health care. This paper presents the key findings from ten focus groups held to explore public views about choice in health and health care and aims particularly to describe attitudes to choice among people living with a long-term condition. It concludes with a discussion about the implications of findings for emerging policy. The findings will inform the design of a larger quantitative survey about choice, to be conducted towards the end of 2005.

This is a piece of independent research conducted by the authors at the King's Fund based on a Pfizer initiative. The King's Fund is an independent charitable organisation working for better health. Pfizer is committed to creating healthcare partnerships to the benefit of patients.

Published by:

King's Fund
11–13 Cavendish Square
London W1G 0AN
www.kingsfund.org.uk

© King's Fund 2005

Charity registration number: 207401

First published 2005

All rights reserved, including the right of reproduction in whole or in part in any form.

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

ISBN 1 85717 495 x

Available from:

King's Fund
11–13 Cavendish Square
London W1G 0AN
Tel: 020 7307 2591
Fax: 020 7307 2801
Email: publications@kingsfund.org.uk
www.kingsfund.org.uk/publications

Edited by Eleanor Stanley
Typeset by Grasshopper Design Company
Printed in Great Britain by CGI Europe

Contents

About the authors	iv
Introduction	1
Policy background	1
About this paper	4
Findings	6
Theme 1: General attitudes to choice	6
Variation in awareness and enthusiasm about choice	6
Loyalty to the NHS	7
Choice and consumerism in health care	7
Multiple causes of scepticism about choice	8
Theme 2: Recent experiences of choice in health and health care	9
Choice about managing different types of health problem	9
Choice between different providers of care	10
Choice about out-of-hours and urgent care	11
Theme 3: Future choices in health and health care	12
Future choice between providers of primary and elective care	13
Direct payments	14
Direct access to specialists	16
Enhanced choice and public health sensibilities	17
Theme 4: Professional support and information for choice	18
Sources of information	18
What information people would like to see	19
Professional support for informed choices	20
Theme 5: Choices about long-term conditions	21
Continuity and trust within the patient–health professional relationship	21
Expert choosers	22
Direct access to specialists	23
Discussion	25
Services outside hospital	26
Use of direct payments	27
Services for long-term conditions	27
Future work on choice	29
References	30
Linked publications	32

About the authors

Rebecca Rosen works half time as a Fellow in Health Policy at the King's Fund and half time as a GP in south-east London. She trained in public health and health services research and worked within both the NHS and academic public health departments before joining the King's Fund. Her current health policy interests include improving care for long-term conditions, new professional roles in primary care and access to specialist care. Her work on long-term conditions spans national policy analysis and the local organisation of chronic care services in primary care. Rebecca is a trustee of Asthma UK and Chair of a small charity promoting closer relationships between scientists and artists.

Natasha Curry is a Researcher in Health Policy for the King's Fund. She has recently been involved in the development of a risk prediction system for the NHS and research into the use of accident and emergency departments. Natasha previously worked as a consultant at a public sector research and consultancy company, prior to which she was the evaluation officer at the Chinese National Healthy Living Centre. She has an interest in black and minority ethnic groups and their access to health services.

Dominique Florin is a health policy analyst with a special interest in primary care, and an inner city GP.

Introduction

In 2001, the Labour manifesto promised to give patients more choice (Labour Party 2005, p 56). The extension of choice in health care is seen as a way of meeting patient expectations, improving efficiency, reducing waiting lists and strengthening local accountability. Choice is not a new phenomenon in the NHS. Patients could choose which hospital they wanted to go to until the 1990s, and the right to choose between GPs has always existed in theory – albeit limited by under-provision in many areas. Nevertheless, extending patient choice is one of several levers in the government’s programme to modernise the NHS as it strives to create a more personalised, responsive and efficient health service.

Four years on from Labour’s manifesto, the drive to increase choice is gaining momentum. By the end of 2005, all patients needing an outpatient appointment will be offered a choice of referral to one of four hospitals. By 2008, every patient who needs to be referred by their GP for a specialist outpatient consultation will have a choice of any provider that can offer care at NHS tariff rates, including NHS, private and public–private providers (Department of Health 2004d). But what does choice mean for people with other types of health problem? Improving care for people with long-term conditions is another key focus of current health policy. For this group, a choice between different providers is less important than the ability to choose between treatments and to access reliable local services that are responsive to their needs and preferences. What about choice for people seeking emergency care? How best can choice be extended to address the needs of these groups?

Policy background

A number of factors have limited the development of choice in the NHS. Payment mechanisms have restricted patient movement and limited clinical capacity to support choice and, in the prevailing culture, patient preferences have often been neglected. The NHS Plan introduced a range of policies designed to tackle these failures. Of particular importance are the financial mechanisms encompassed in Payment by Results (Department of Health 2002b); capacity increases associated with the programme of independent treatment centre procurement (Department of Health 2002a); the introduction of the Choose and Book IT system (Department of Health 2004b) and associated initiatives to support choice at the point of referral.

With every patient being promised a choice of four providers from the end of 2005, and exacting waiting list targets (a maximum of 18 weeks from referral to completed treatment), the pressure to make patient choice a reality could barely be greater. Choose and Book pilot programmes have demonstrated that the infrastructure is falling into place for electronic booking at referral – albeit at a slower pace than initially planned (National

Audit Office 2005). Two pilot projects – The London Patient Choice Programme and the National Coronary Heart Disease Choice scheme – demonstrate patients' willingness to exercise their right to choose.

With necessary policies in place to support choice, the next step has been to find ways to make them work. The Department of Health consultation on *Choice, Responsiveness and Equity* (Department of Health 2003) explored how to extend choice across all areas of the NHS. Building on the work of eight task groups, the consultation identified several areas for development, including improving access to information about providers; better support for choice for patients with long-term conditions; improved end-of-life care and maternity services; more choice over treatment and access to medicines; and access to a wider range of services in primary care.

At a local level, PCTs, acting in their commissioning role, are trying to establish contracts with four or five providers of elective care, although many have faced problems in doing so (Harding 2005). A recent study to map choice in the NHS found that opportunities to exercise choice varied geographically, influenced by the interaction between spare-bed capacity, demand and need. (Damiani *et al* 2005). Proposals to increase capacity through independent sector treatment centres (ISTCs) specialising in elective surgery and outpatient care are progressing relatively slowly, with only five such centres fully operational by mid-2005 (Department of Health 2005a). Focusing on elective care and using private sector business techniques and incentives (Dash 2004) these centres are intended to provide faster and more flexible services. However, evidence to date of additional capacity from these providers to support choice remains weak (Appleby and Harrison 2005).

What is already known about patient choice?

To date, approximately 20 per cent of people waiting more than 6 months and offered choice for a planned operation have chosen a provider other than their local hospital (Department of Health 2004a), although this figure was over 60 per cent for those offered choice after waiting more than six months through the London Patient Choice Programme (Burge *et al* 2005). Evidence from this pilot programme provides insights into public responses to choice. Participants in the programme took various issues into account when deciding where they would choose to receive health care services. These included waiting time, travel and transport arrangements, the reputation of the establishment and follow-up arrangements. They were prepared to tolerate longer waits to attend hospitals with a better reputation and shorter travel times (Burge *et al* 2005). The Department of Health is currently preparing information about different providers into user-friendly, easily accessible summary formats to help people to make their choices.

Several other studies have explored public attitudes towards recent policies to increase choice. In 2003, MORI conducted an extensive survey in the Midlands of patients' and clinicians' views on choice (MORI 2003). The study revealed low public awareness of the choice initiative, but people were positive about the principle behind choice, albeit with concerns around its practical introduction. A second MORI study (Worcester 2003) and the British Social Attitudes survey (Appleby 2005) found that the majority of the public would like more say, particularly in their choice of hospital.

The British Social Attitudes survey also revealed some surprising – and perhaps counter-intuitive – results. In particular, it found that older people and those on lower income groups were more pro-choice than younger people and those on higher incomes. Similarly, there was more enthusiasm for choice among those with lower or no educational attainment than those with higher qualifications. Aside from these findings, little research exists from which to predict the impact of current policies on equity of access to health care. This indicates a crucial need to monitor the impact of choice on different socio-demographic groups.

Choice and the wider policy environment

The principle of choice has extended well beyond elective care. *Building on the Best* (Department of Health 2003) heralded the extension of choice into primary care and pharmacy services. The forthcoming consultation on care outside hospitals will accelerate this process, although existing changes to the regulation of primary medical services and the new pharmacy contract already create significant opportunities to diversify and expand the provision of primary care services (Department of Health 2004e, 2005c; National Association of Primary Care 2004). *Choosing Health: Making healthy choices easier* (Department of Health 2004c) presents the government's strategy for improving public health. It emphasises the role of personal choices in the prevention of illness and promotion of well being.

At the same time, emerging policies on long-term conditions and people with complex health and social problems, are highly relevant to the choice agenda (Department of Health 2005d, 2005e). A number of recent pilot schemes in social services have offered people with complex health and social problems the option of receiving a cash payment instead of a directly provided service. These 'direct payments' aim to give people more control over the services they receive, enabling them to choose between different providers and to develop a highly personalised package of care. While uptake of direct payments has been patchy, satisfaction with the opportunities they create has been high (Riddell *et al* 2005), and questions arise about whether and how to extend this approach into health care.

Supporting self-management of long-term conditions is another key element of current policy and a recent review of patient views on this subject revealed strong preferences for involvement in choices about diagnosis and treatment (Corben and Rosen 2005).

Many questions remain unanswered about the expansion of choice within the NHS. How will the public – shown thus far to be largely unaware of the issue and, frequently, indifferent to it – react to this new opportunity? Will people be more enthusiastic about choice in some areas than in others? How will the government and NHS organisations respond to the introduction of greater choice (with its foreseeable and unforeseen consequences)? What will be the response to hospital failures that may arise as a result of choice, and what regulatory framework will encourage innovation without excessive destabilisation? What does choice mean beyond choice of provider?

The answers to these questions will only become apparent once the public starts to make choices in health and health care. Yet successful implementation of current policy will

require us to understand and respond to public views and preferences about choice in health and health care. Future policy to extend choice into other areas of health and social care must also be informed by public opinion and reports of early experiences of choice.

About this paper

This paper presents qualitative research into attitudes to choice in health and health care expressed by members of the British public during focus groups held in England, Scotland and Wales during the summer of 2005. It seeks to assess the extent to which the public welcomes choices that have recently become available in elective and primary care, and to explore attitudes to the choices that are likely to emerge from forthcoming policy on care outside hospital, out-of-hours care and the further expansion of independent sector providers of health care.

The paper aims particularly to describe attitudes to choice among people living with a long-term condition. Patient groups representing people with long-term conditions see enhanced choice as just one element of the changes needed to improve quality of life (Partnership on Long Term Conditions 2004). With around 60 per cent of people living with long-term conditions such as diabetes and depression, the views of this group are particularly important and were explored during focus-group discussions.

The paper also aims to explore attitudes to two more choices that are not encapsulated in current policy. The first of these is the use of direct payments as a way to enable people to make choices about the health services they want and who they want to provide them. Currently only used in social care, the extension of direct payments to health services is under discussion among policy makers but has not yet been introduced. The second is the ability to choose to go directly to a specialist without the need for a GP referral, as is possible in many other countries.

The report presents key findings from ten focus groups held during June and July 2005 to explore public views about choices in health and health care. Findings are presented around five key themes:

- general attitudes to choice
- recent experience of choice in health and health care
- future choices in health and health care
- professional support and information for choice
- choices about long-term conditions.

It concludes with a discussion about the implications of findings for emerging policy. The findings will inform the design of a larger quantitative survey about choice, to be conducted towards the end of 2005.

Research methods

In order to explore the public's attitudes to choice, a series of ten focus groups were run across the country. Groups ranged in size from four (a carers' group) to ten people. MORI was commissioned to recruit a diverse range of participants from locations in England, Wales and Scotland. Focus groups were held in both urban and rural locations.

Range and locations of focus groups were as follows (all groups were of mixed gender):

- Exeter rural, aged 55+
- Exeter city, aged 20–50
- Leeds rural, aged 50+
- Leeds city (carers of children), all ages
- Edinburgh, aged 30–55
- Rugby, aged 45–65
- London (carers of adults), all ages
- London (long-term conditions), all ages
- Maidstone (long-term conditions), aged 20–35
- Cardiff, aged 20–45.

Two groups specifically involved carers of adults and children, while a further two groups involved people with at least one long-term condition. In the remaining groups up to half of the people participating were living with a long-term condition, in line with the prevalence of long-term conditions in the general population. The groups were intended to capture a wide range of public opinion, although it was recognised that ten focus groups could provide only a flavour of commonly held views.

At the start of each session, the facilitator introduced the project and outlined the reasons for undertaking the research. The discussion was then structured around three key areas, exploring:

- participants' attitudes to choice in general
- current and recently made choices about health and health care
- the choices they would like to make in future, including choices about primary care, planned operations, direct payments and direct access to specialist care.

Findings

Theme 1: General attitudes to choice

- There was wide variation in participants' recognition that choice exists and in enthusiasm about extending choice.
- Many people had an underlying loyalty to the NHS, with a preference for further investment in current services over developing new providers.
- There were various causes of scepticism and uncertainty about choice.
- People saw a distinction between consumer-type choices in health compared with choice in other walks of life.

The choices we make, and the ways in which we make them, are heavily influenced by our personal characteristics, preferences and prior assumptions. Some people research each choice in detail while others reserve this effort for major decisions only. Some enjoy making choices while others do not. What is more, some have the financial and personal resources and the time available to identify and research different options, while others lack the means to do so.

Certain views about choice in general, and specifically in relation to health and health care, were commonly held and expressed by participants from all ages and all walks of life:

- widely varying levels of awareness, understanding and enthusiasm about choice
- a sense of loyalty to the current NHS
- views about choice and consumerism in health care.

Participants' views in relation to these issues are described below.

Variation in awareness and enthusiasm about choice

The majority of focus groups started with participants denying that choice exists beyond the (often unaffordable) choice between public and private providers. With prompting, they typically acknowledged that many of their day-to-day decisions (for example, about diet, medications or the management of minor illness) were, in fact, choices about health and health care, although they did not naturally see them as such. One participant complained that 'choice' was a 'vague word – nothing specific', adding, 'It doesn't really mean anything to me'.

Once stimulated by the focus group discussion, there was considerable enthusiasm for more choice in health and health care. Many participants were active choosers in all

walks of life, adept at researching the choices they faced and logical in their approach to obtaining information and considering the pros and cons of different options. The internet was often mentioned as a source of information to support choice; however, many participants, particularly those who were older, reported that they had no idea how to use the internet and had to ask a friend or relative to find information for them.

In contrast, some participants expressed the view that people are simply not used to making active choices and may not always want to choose. One described our collective experience of the NHS as having been brought up in a ‘nanny state’ in which we have become conditioned to the health service taking care of us and reluctant to make choices for ourselves. Another described feeling wary about having choice:

Sometimes you can have too much choice. It's like being in a sweet shop and not knowing what you want.

Loyalty to the current NHS

In almost every group, some participants expressed the opinion that it was wrong to extend choice between the NHS and new providers because it would undermine the NHS (as we know it). They argued that the money and effort invested in supporting new providers would be better spent improving those that already exist. Typical comments were:

Just improve what is already there, rather than adding more and that getting worse.

I don't actually want choice. All I want is good quality.

These views were aired repeatedly – particularly during discussions about the desirability of increasing the range of health care providers. However, some participants who expressed these opinions were also enthusiastic about the potential benefits of choice at other points in the discussion, demonstrating their capacity to hold apparently contradictory views.

Choice and consumerism in health care

The majority of participants perceived important differences between choices about health and health care and other consumer-type choices – that is, choices between different products and services. They attached greater importance to such choices about health, and feared significant consequences of making the wrong choice:

It's different because you are talking about health, which is far more important than any hi-fi or car. Health is more important than anything really, so you need to go to someone who knows about health.

Participants explained the differences between choices in health and health care and other consumer choices in many ways. These included the limited knowledge base among health care consumers and the importance of seeking advice. Many preferred to leave health care choices to the experts, despite their willingness to make other consumer choices – even about expensive objects – without professional advice. Some felt that sales people for consumer goods would not hold back product information, while doctors may not mention treatments that they see as expensive or ineffective. Others observed that,

unlike consumer choices, choices in health care have no price attached to them for the patient. However, they agreed that knowledge and information were needed to support all consumer choices, in health and in other walks of life:

Health care is something you need rather than something you want, and there is an imbalance of knowledge and information in the health sector that is harder to bridge than in the world of consumer items.

When it comes down to the actual 'yes' or 'no' about a treatment, I give my opinion, but I would leave the final decision to the specialist who knows about it. It's not like buying a car at all, and I don't think you can compare them.

Another important distinction was the consequence of 'wrong' choices and the idea that living with the consequences of a poor health choice could have significant effects:

It would probably damage you psychologically if you felt like you didn't get the best treatment.

Multiple causes of scepticism about choice

Participants raised a range of points demonstrating scepticism about the value of choice and its effectiveness at improving services. Their concerns included the bureaucracy associated with enabling choice and the illusory nature of choice when there is insufficient capacity to support it. They also described experiences of health professionals withholding information about selected options and thus reducing the breadth of choice available.

These concerns are illustrated in the following quotes:

The more complicated they make it and the more bureaucracy, the more pen pushers there are and the less money is actually getting to people... to the customers.

If you are going to be able to make choices, there has to be spare capacity – and if there is spare capacity, why is there such a long waiting list?

There are so many drug treatments now available for certain things that they won't offer you because it will cost them money. So you actually have to say, 'My choice would be...'. I want the best medication that I could get.

Only a handful of participants had a clear understanding of the way choice operates in the context of markets in health care. However, various participants voiced opinions that related to this subject. Some recognised that competition could help to drive up standards. A few pointed out that by exercising choice, patients could cause a hospital to shut down or create long waiting lists for popular consultants. Meanwhile, others were aware that perverse incentives associated with NHS payment systems could distort good practice. One participant asked:

Is, let's say, a private hospital likely to share best practice? If they are really good and they help people down the bottom of the table, they are going to lose customers and are going to lose their bonus. So they won't share their good ideas.

Theme 2: Recent experiences of choice in health and health care

- Judgements about the severity of a condition are a key influence on choices about when and where to seek professional advice.
- Recent choices between different providers had typically been influenced by well-recognised factors, such as convenience, reputation and accessibility.
- In out-of-hours care, people made complex judgements based on type of problem, past experience, knowledge of available services and likely waiting time.

Discussions about current and recent choices highlighted how frequently people make choices about health and health care, but how little they see themselves as active consumers whose decisions may influence the services they receive. As the discussion progressed, these views began to change, with growing acknowledgement that their recent decisions were examples of active choice.

Many participants became enthusiastic about making more choices in future, but remained sceptical about the likelihood of being offered the full range of available choices. They emphasised the importance of obtaining and interpreting information about different services (*discussed in more detail in Theme 4: Professional support and information for choice, p 18*). They also highlighted various constraints on the choices they were able to make.

The discussions on this theme centred on:

- choices about managing different types of health problem
- choices between different providers of care
- choices about out-of-hours and urgent care.

Participants' views in relation to these issues are described below.

Choice about managing different types of health problem

Participants had made choices across a wide spectrum of issues – from prevention and health promotion through diagnosis of unknown problems to the management of existing conditions. Choices about prevention lay partly in well-recognised domains, such as lifestyle choices about diet and exercise. They also required complex judgements about avoiding deterioration in established conditions.

The value of professional advice and trade-offs between several well-recognised desirable attributes (convenience, quality, continuity and so on) were also evident in treatment choices, both in terms of choosing which treatment to have and in choosing when and where to have it, as the following comments illustrate:

You want the choice of going somewhere quickly when you need to, but you also want continuity from your own doctor when you need that.

Oh, I'd want the best person to do the operation. I'd wait for that. There are times when you want the best, and other times when you are happy to have the next down the ladder. It depends how routine it is.

On a related note, participants made clear distinctions in the way they made choices about different types of health problem. They described judging the severity of their problem, with different strategies for dealing with minor ailments and more serious symptoms. For minor problems that disrupted normal routines, such as a nose bleed or a sprained joint, several participants had used conveniently located, rapid-access clinics (such as walk-in centres) if they were available. Participants from rural areas were at a disadvantage here, with few alternative providers to their local GP. The majority described having used over-the-counter treatments on the advice of a pharmacist for minor ailments:

For something minor, I'd go to the chemist, but if it was more serious and had gone on for a while, I'd go to the GP if I could get an appointment.

Most of those who had experienced more serious or harder-to-interpret symptoms, such as tummy pain or bad back ache, said they had chosen to see their GP, although some said they would be willing to see any doctor, or other health professional, who was competent to look after them. Many participants stressed the importance of continuity of relationship with their own GP. The knowledge held by the GP about their medical history and personal and social circumstances were widely seen as important to support diagnosis and treatment of all but the most trivial complaints.

Choice between different providers of care

Differences in choices made about different conditions influenced the choices made between different providers of care. Participants had used pharmacists, practice nurses, walk-in centres and self-management for minor problems, either instead of, or in addition to, visiting the GP. Pharmacists were widely appreciated for their accessibility and knowledge and for the convenience of accessing advice without a trip to the GP. Participants often bemoaned the inflexibility of GP clinic times and appointment-booking processes, and were enthusiastic about other conveniently located sources of primary care for minor ailments.

Say you suddenly get food poisoning, you want to go out and get something quickly to settle your stomach and then go back to work. You don't want to book an appointment to see your doctor.

I use a pharmacist myself. I was there many times because he's given better advice than a doctor.

Many participants had experienced the frustration of choosing to see the GP then not being able to get an appointment. Some had found that phone lines were permanently engaged, others that all the appointments had gone by the time their call was taken. A handful reported that if their GP had not been available, or the wait for an appointment had been too long, they had chosen to go to their local accident and emergency (A&E) department:

When my children were younger, I tended to go to the children's area at St Mary's. I felt safer going there and having them thoroughly checked out than the GP saying it was a virus and giving them antibiotics.

Only one participant reported having exercised choice about his GP practice. Several saw the days of having a single GP whom the patients knew, and who knew the patients, as

past. Most perceived that there was no choice. Some knew that choice was available in theory but limited in practice due to closed lists and under-provision of GPs.

In Maidstone, you don't even have a choice of GP – it is decided by what area you live in.

In relation to choices about elective surgery, a significant minority of participants had already experienced the opportunity to choose between different providers of elective surgery, as NHS patients. A range of well-recognised influences had shaped their decisions including waiting time, convenience, the reputation and expertise of the clinical team that would provide care, and the proximity of different institutions to their carers.

Participants had taken different approaches to deciding where they wanted to go. Some relied solely on GP advice while others used lay networks to explore the reputation of different hospitals. Still others tried to identify objective information by which to judge different hospitals – a subject explored in more detail in Theme 4: Professional support and information for choice (p 18). Several had been offered the choice of a private-sector provider, which they had accepted for various reasons, including short waiting time and preferable hotel facilities. There was also a general belief that private was better, and that MRSA is less of a problem in smaller private hospitals:

I don't know if anybody else saw it on the news last week – there was lady who wanted a scan and she had to wait 18 months for it. She went private and she could have it in two weeks.

I was worried about MRSA. I didn't want to go to a big hospital, and the private hospital was smaller. Also, they had a pre-op clinic there, and they tested you with a mouth swab beforehand for MRSA.

Choice about out-of-hours and urgent care

Views on out-of-hours care varied enormously, depending partly on geographic location and the availability of different out-of-hours facilities. Those in rural locations could typically only choose between their usual doctor and A&E, while others had access to minor injury units and walk-in centres.

Participants' choice about which out-of-hours service to use was influenced by various factors, including judgements about the length of wait in different settings, their knowledge and previous experience of different local services and ease of access to different providers.

Many participants had used the medical advice line NHS Direct. Their experiences were mixed. Some reported having received adequate or good advice over the phone, while others had had to wait a long time, had received advice that they considered inappropriate, or had been referred on to other services that they could have contacted in the first place.

When asked about their views on a single point of access to all urgent care services via a national phone number, participants voiced a range of fears. These included problems getting through on phone services and the risk of a long delay between contacting the

service and being called back. They were also concerned about the difficulty of describing symptoms accurately over the phone, the possibility of incorrect diagnoses being made over the phone, and fear about what happened if you disagreed with the advice given over the phone.

There was sometimes a view that in an emergency, calling 999 or going to A&E would be more straightforward, but that this was a problem for those without private transport. For less urgent problems, participants defined a need for a middle ground between A&E and doing nothing, but there was little consensus on whether telephone triage services filled this space appropriately.

Maybe you underestimate what is wrong with your child, and for someone to be able to tell on the phone is ridiculous. I want to be responsible for the health of my child. I think it is good that NHS Direct is there, but it has to be your choice whether you think you can trust it.

Furthermore, some had experienced the constraints on choice of not being able to access certain services. For example, the local out-of-hours service had failed to respond to one participant's request for a home visit but the choice of an alternative, more distant, provider was impossible for her to use:

I don't drive, I'm on my own and I don't have any money. So I couldn't get my child seen at hospital, and they still wouldn't come out.

Theme 3: Future choices in health and health care

- **Many participants were enthusiastic about access to a wider range of primary care services but there was a recognition that people will be more likely to attend for minor problems.**
- **There was variable interest in the idea of using direct payments as mechanism for exercising choice. This was linked to concerns about the complexity of decisions and information that would be required.**
- **Participants generally held mixed views on direct access to specialist services. Although there was some enthusiasm for easier access there was concern about how to choose which specialist to see and about encouraging attendance for minor problems.**
- **There was a sophisticated awareness of the tensions between increasing access and choice and the possibility of stoking demand for services.**

The groups discussed areas in which there may be greater opportunity for choice in the future. First, they talked about the choices that will emerge from current policy to develop a market, with multiple competing providers of primary care and elective surgery. The groups also discussed extending choice in the future to include direct access to specialists and various forms of direct payment for services.

There was no clear consensus about any of these broad topics, but there was agreement about some sub-themes. There were variable levels of interest in each of the future

choice domains discussed, and participants identified a cluster of concerns about each of them. As highlighted earlier, many voiced the view that it would be better to resolve problems with current NHS services and ensure universal access to a reliable local NHS provider than to extend choice between different services. They expressed concerns about the overall impact on the NHS of broadening choice, described in ‘Enhanced choice and public health sensibilities,’ p 17.

Key themes in relation to future choice were:

- future choices between providers of primary and elective care
- direct payments
- direct access to specialists
- enhanced choice and public health sensibilities.

Participants’ views in relation to these issues are described below.

Future choice between providers of primary and elective care

All NHS users will soon face choices between providers in two particular areas: elective care and primary care. Participants generally welcomed the opportunity to choose between different elective care providers – particularly in the possibility of choosing a private hospital. However, one person noted that increasing choice would not necessarily increase quality:

You can have three high-quality choices, or you could have eight bad ones. Just because you’ve got more choice doesn’t necessarily make it better quality.

Many participants valued the opportunity to prioritise factors such as the accessibility of the site and the length of wait when making their choice. Others stated that the general reputation of a hospital would most influence their choice, while others said they would choose to go to the best clinician they could find. A small number valued the opportunity to choose, in order to avoid certain institutions:

I’ve had two bad experiences at one hospital, and I don’t want to go back there.

However, many felt poorly equipped to make such choices on their own, referring often to the professional advice they would need to make their choice. One participant explained:

It would be nice so long as the doctor said that such-and-such a hospital would suit you better.

When asked if he would feel more comfortable if he were able to tap into a GP’s knowledge and advice, the same participant responded:

That’s right. I couldn’t just go home and look it up. The GP should be able to give you a print out saying such and such takes x weeks, such and such takes y weeks. So then you have a choice.

These issues are explored further in Section 4: Professional support and information for choice, p 18.

When it came to choosing between a wider range of primary care services, participants held a range of views, but two key themes emerged:

- the high value attributed to convenient access for minor ailments
- perceived problems with consulting about more serious health problems with a clinician who lacked access to a continuous medical record or prior knowledge of the patient.

In every group, people welcomed the idea of easy-to-access primary care clinics close to work, travel or shopping facilities. They re-emphasised the distinction noted above between minor problems that it would be appropriate to take to such clinics and other problems that required continuity of relationship with the doctor:

It is an issue of trust as well. Going to a clinic in Tesco rather than seeing a GP who I have seen for several years, where I have built up a relationship – I might trust them with a cold or something, but not much else.

Many participants were sensitive to the high workload of GPs and the potential offered by a new breed of easy-access primary care providers to divert minor problems away from GP surgeries, freeing up time to attend to patients with complex, ongoing problems.

Some comments indicated that thresholds of severity for attendance may drop in line with the barriers to obtaining access, so that drop-in clinics could create additional use of services for more minor complaints rather than replacing existing use of GP services:

If you get a sore throat and you feel that you don't want to go to the doctor, you could just get it checked out at the drop-in clinic.

I think perhaps I would be more inclined to use the drop-in medical centre. Sometimes you have a shopping list of things that are needed rather than real problems, and it would be good to talk.

Some participants – particularly those who do not experience continuity or convenience at present – felt they would not have much to lose by going to new primary care providers:

At my GP practice, there are five or six doctors we can see. A while ago, you could say, 'Can I see Dr so-and-so?' but now you can't. So you're not seeing the same doctor all the time anyway.

If my child is sick, I will see anyone.

Direct payments

The concept of direct payments as a mechanism for exercising choice was unfamiliar to many participants and was explained in terms of being given a cash allocation to buy services directly or a 'cash equivalent' voucher, to be used to obtain a service with payments made by the health service. These were discussed in relation to single services (such as physiotherapy or chiropody), in relation to people with long-term conditions buying a package of specialist 'disease management' services, and in terms of having a voucher to buy an annual comprehensive package of care – equivalent to being able to choose between different health care purchasers. Only one participant had experienced direct payments – in their case, for social care.

On the issue of direct payment for single therapies, participants held mixed views. Several reiterated their commitment to improving existing NHS services rather than choosing other providers:

If the whole system was better, you wouldn't need all this.

Others, however, saw the potential for greater flexibility. One participant asked:

Can you make the choice for them to come to your house?

Many asked how people could ensure that the practitioners who they were spending their money on worked to a high standard. Some expressed concern about the risk of paying for alternative therapies from 'quacks' and 'charlatans' and highlighted the need for regulation of professional standards:

We need to know that people who are saying they are qualified to work in these areas are under some sort of surveillance and are not just in it for money.

Asked specifically whether they thought it would be acceptable to 'top up' the value of the vouchers to obtain a more expensive service. Many said 'yes', though some argued that this would be unfair. Many thought it acceptable to use vouchers to obtain alternative therapies even if there was no evidence that they were effective. Indeed, some participants equated this freedom with their own past decisions to pay for alternative therapies. Conversely, some thought it unreasonable to spend public money on therapists who may be 'cranks'.

The idea of direct payments as a mechanism to choose between different providers of specialist care for long-term conditions was confusing for some participants. Even among those who were living with the conditions, few had heard about specialist disease management services for conditions such as diabetes and asthma. When introduced to the concept of specialist organisations working mainly over the telephone to manage a specific condition such as diabetes, some expressed an interest in the idea, while others raised a number of concerns. These included the potential for fragmentation of care for people with several conditions, and poor communication between disease-management organisations and their usual health professionals. Several expressed reservations about receiving services over the phone and stated a strong preference for face-to-face encounters. Others highlighted the difficulty that they felt they would face in gathering, interpreting and acting on information in order to choose between providers.

Two participants saw the use of vouchers for whole annual packages of care as being similar to choosing an annual insurance policy. They felt this was less daunting than having to select between many different health care providers independently. Others felt that the choice would be too complicated and would require complex information to support it.

If you are asking, 'Do you think people would mind researching this?', I don't think people would have a problem with that. It might sound a bit daunting when you lay it out like that, but when you actually have a list of things in front of you I don't think it would be.

However, many participants felt the voucher system seemed unnecessarily complicated, bureaucratic and resource intensive:

I could say it's a complete waste of time, effort and money in order to create a second system, which you would have to enforce or police. I mean, what's the point? We have the NHS; it's there, and everybody uses it.

Direct access to specialists

Participants expressed a range of views about choosing to go direct to a specialist without first seeing a GP. Several changed their views as the discussion developed, initially welcoming the idea as 'brilliant' or 'great' – particularly if the arrangements would mean reduced waiting times. However, doubts set in, particularly in considering how to know which specialist to go to:

With a skin rash, it's pretty obvious where you'd go, but say you had a tummy pain there could be a number of different reasons, and you would have to decide what kind of doctor you saw.

If you are feeling really unwell, you don't know what's wrong with you. What specialist would you go to? You need to go to your GP and let them look at your symptoms and tell you where to go, or go to A&E.

But many participants were also concerned about the capacity of specialists to cope with demand and the effect of people going to see specialists with trivial problems. Some felt that GPs played an important role in deciding whether a problem was serious enough to merit specialist intervention:

I think there would be a long waiting time because people would go with very minor things.

People might go and bother a specialist when it was something they could sort out themselves. You get that now. You always get hypochondriacs.

Another concern related to fragmentation of care and the recurrent theme of lacking access to a complete medical record:

You go and see a specialist, and they don't really know what is right for you and what isn't. I got some treatment. The doctor wrote a prescription for me, but I was seeing the diabetic nurse at the time. She took one look at the prescription and said, 'You can't give him that – he's allergic to it', but I didn't know I was allergic.

People with long-term conditions added a different perspective. Several had experienced delayed diagnoses because their GP lacked knowledge or experience about their problem:

I think when you don't seem to be getting anywhere, after seeing a doctor three times in four days and nothing they give you is working, and then they refer you and you have to wait, you should be able to say, 'I want to shortcut the system here.'

Many of the participants with long-term conditions had already obtained direct access to specialist advice and opinion – an issue discussed further in Theme 5: Choices about

long-term conditions, p 21. Some had developed direct links with the one or more members of their hospital team that enabled them to bypass the GP when they needed advice or care:

I go straight to my consultant, but that's because I have regular appointments and they say, 'Phone within so many months if you want an appointment.' There is no point going to my GP.

Enhanced choice and public health sensibilities

A concern raised in every focus group was that enhancing choice would lead to a waste of resources. This was particularly evident in discussions about direct access to specialists and, to some extent, regarding enhanced choices of primary care providers. There was a widely and strongly expressed concern that such increased choices, while possibly of individual benefit, would be collectively detrimental, diverting resources from people with more severe problems.

People would take up the specialists' time where they could be dealing with more important things.

You are always get people who push themselves in front of the queues. There are always hypochondriacs.

This finding could be thought of as an internalised public health sensibility, reflecting an awareness of the need to control cost and support fair distribution of scarce NHS resources. This is, however, in direct contrast to their enthusiasm for, and willingness to use, these new providers for minor ailments.

Participants' concerns about the tension between welcome improvements in access and convenience and the potential consequences of making access too easy were striking. The findings suggest that promoting an individualistic choice agenda could override concerns about lowering the thresholds of severity that justify medical attention. This, in turn, could reduce the degree of self-restraint exercised by some in the use of limited NHS services:

Some people will go straight to the specialist with a heat rash or something while people with really serious conditions couldn't get there. It would be lovely if there were that many specialists that you could do that, but I have trouble just talking to the secretary of my consultant. They are way too busy to get through to them, for weeks on end. If there were even more people, I'd never get through.

The specialists are the heads – the big-wigs – and you don't want to waste their time if you are going, if it is just a bit of tummy ache from PMT and all. Somebody else might drastically need that care.

Theme 4: Professional support and information for choice

- Participants held a universal belief in the need for a wide range of information about different services.
- Participants' levels of skill in obtaining and interpreting information varied.
- There was near-universal agreement that information is of little use if health professionals are not available to help interpret it and to provide advice.

Access to information has already been highlighted as a recurrent theme throughout all focus groups. Without exception, participants stated that having a choice is meaningless without access to understandable, relevant and high-quality information. In addition, this factual information is problematic unless expert advice is available to help people to interpret and process the information and to support personal choices about health care.

The discussions on this theme centred on:

- obtaining information for choice
- what information people would like to see
- professional support for informed choices.

Participants' views in relation to these issues are described below.

The majority of focus group participants felt that they did not have access to sufficient information to allow them to make choices:

Only if we have more information to make these decisions [do we want more choice]. They have a lot of specialist knowledge in that profession and without that specialist knowledge you can't make an informed decision and it is a massive responsibility for us to make our own decisions and not know what we are doing.

Participants of all ages and from all backgrounds stressed the importance of their own clinical information being available during a clinical encounter. They felt that it was important that, for all but minor ailments or very urgent problems, the health professionals who treated them should have access to their clinical record. When discussing the possible introduction of new primary care providers in convenient, easily accessible settings, such as shopping centres and stations, a common concern was that the doctors would have no clinical information about the patients who attended, nor any prior personal knowledge or relationship:

I just don't think they would be able to do it. A lot of it is to do with personal care as well. If you are just walking into a clinic in Tesco, they have no knowledge of your background and medical history.

They wouldn't be able to prescribe you something because how would they know if it will react to something else you are taking?

Sources of information

Most people cited their GP as their principal source of information, with most relying completely on the GP or consultant to provide the information they need. In addition, there was a significant group of people – usually, though not exclusively, older – who said they would not know where to go to obtain more information.

A small number of participants had used the internet to research specific conditions or procedures, but there was general scepticism about the reliability of information found online. Some said they would feel comfortable using the internet, medical journals and patient advisory and liaison (PALS) services to access information to support their choices, but there was marked variation in people's level of confidence in seeking out information for themselves. Many older people were aware of the potential of the internet as an information source but felt they would not be able to use it themselves. Some said that family members may be able to access information on the internet to give to them, but others were less certain:

I wouldn't have a clue. I do ask people to look at the internet for me, but I wouldn't know what to do myself.

Even some individuals who felt confident in sourcing information online were cautious about it:

It's not that simple, the internet. Sometimes, you have to know what you are looking for before you get the right information.

Where people had experienced a choice of hospital or procedure, most had relied on word of mouth to judge the reputation of a hospital, along with GP advice, rather than undertaking any internet-based or other research themselves. The experiences of family and friends, along with information available in the media, appeared to have most influence on the choices people made. Two people cited pharmacists as sources of information about conditions and appropriate services.

Although most participants were keen to access more information, they still emphasised the important role of the health care professional. A clear message from all the focus groups was that information on its own is not sufficient and that there cannot be more choice without better means of interpreting it. Informed advice was seen as key to the effectiveness of the choice agenda. Some people felt that, with the right information and appropriate support, they could become active consumers of health care.

What information people would like to see

The majority of participants wanted more information, in more varied formats, backed up by professional advice. With regard to choice of elective provider (hospital), people were particularly interested in gaining access to information about:

- waiting times
- quality and outcome measures
- operation 'success rates' (by hospital and consultant) and quality of aftercare
- transport services
- parking
- distance from home
- facilities for visitors
- MRSA rates.

However, they did not have strong views about the type of information they would want in each category, nor about the format in which it should be presented.

Participants typically felt less able to choose between specialists than between hospitals and were less clear about what information they would require to identify the right specialist. The majority felt that they would not have the necessary expertise or knowledge to judge which specialty they required and would prefer to be directed by a health care professional. Many reported relying heavily on their GP opinion and said they would continue to do so when it came to choosing a specialist:

The doctor can decide if it is serious enough to send you to a specialist, and they can advise you on the better specialist to go to.

Some participants stressed the importance of the context within which the choice is being made. The extent to which people felt able to make decisions about the information they had accessed depended on their personal circumstances and the severity of the condition. The more serious the procedure, the more support and guidance they wanted in making choices.

Professional support for informed choices

Participants repeatedly emphasised the key role of the professional in helping them interpret and process information. Many participants felt that information would be more or less useless to them without input from a health care professional:

If I want legal advice, I don't pick it off the shelf – I go to a lawyer. If I want insurance, I go to a broker. So if I want health care, I will go to the GP.

There's no point in someone giving you the options if the options are not explained when they are given to you. The information has to be made accessible to you by the person who's giving you that list and those choices. They must at least give you a helping hand in making the right decision for you.

Many participants saw the GP as the key source of information, and of the advice and support to interpret that information, although they were concerned that GPs do not have enough time to talk through all information and advise on options.

Others were less specific about who should provide this type of support, although some talked about some sort of advocate, working between the GP and themselves, who would have enough time and an understanding of the patient's personal circumstances to help them make the optimum decision. One group stressed that any advice and support should come from a doctor, not a nurse, as they were not confident that nurses would have sufficient knowledge.

Almost all the groups agreed that information given over the phone was no substitute for face-to-face contact.

I would prefer to talk to someone about it person to person. You would want support and back-up from your GP if it was really serious.

In addition to being able to discuss information with a health care professional, the relationship between the participant and the information provider was thought to be crucial to making a choice. Participants said they would prefer to discuss their choices

with someone whom they knew and trusted and who knew them. Most people said that this person would be their GP, although there were concerns that GPs may not have the time to talk patients through the information:

It's not just the information, but the relationship you have with the health professional.

Theme 5: Choices about long-term conditions

- **People with long-term conditions viewed ongoing relationships with both generalists and specialists as important to support choice.**
- **Some people with long-term conditions have acquired enough knowledge and understanding about their conditions to act as 'expert choosers'.**
- **Many people with long-term conditions had negotiated direct access to specialist advice and could choose when to make use of this.**

People living with long-term conditions typically have more extensive experience of health care services than others. A cluster of themes relating to choice stood out as particularly important to these particular participants. They included:

- continuity and trust within the patient–health professional relationship
- people with long-term conditions as expert choosers
- the value attached to having direct access to specialist advice.

Views in relation to these three themes were gathered in particular from the two groups in which all participants were living with long-term conditions and from people with long-term conditions who participated in other groups. Their views are described below.

Continuity and trust within the patient–health professional relationship

Participants with long-term conditions described more complex needs for a trusted health professional who knows one's personal history and preferences. This was evident in various ways, in terms of their relationships with their GP and their attitudes to new providers of primary care and chronic disease management. Some participants with long-term conditions saw their GP a key advisor who knew them well:

It's difficult to see someone who doesn't know you. You know your GP, and you've seen him over a number of years. He knows you well and your history, and perhaps your family history as well.

However, others described using their GP only for minor problems and turning to a trusted specialist (or team) for expert advice about specific problems with their condition. Those with a rare condition saw generalists as unable to keep up with expert knowledge about their condition. Others had negotiated direct access to a specialist team:

There is someone I have that relationship with at the hospital. I have her bleep number and can get in touch with her Monday to Friday, and she knows all about me. That is really good. It is comforting to know you can get hold of somebody who knows what your problem is.

Despite these relationships with specialist teams, there was still a recognition that GPs can have a key role to play in helping with difficult decisions:

Possibly you would want to have that choice, but most people want their own doctor to tell them x, y or z and they would go along with it.

Regarding new primary care and disease management providers, there were mixed views, with some preferring to stay with their trusted GP while others were attracted to the idea of a proactive new service to co-ordinate their disease management. Some recognised the potential benefits of a highly specialised provider that could stay up to date with new developments in their area:

For some people, disease management would be good, but others prefer face-to-face contact. I know I certainly would. I have had asthma for 15 years and my GP knows my condition inside out – well, he comes across as if he does, anyway. So I feel much more confident and comfortable with that than with some faceless [disease management provider] on the phone.

I don't like the idea of the GP who doesn't really know saying 'do this' and 'do that'. I would rather see somebody who is a specialist in that condition.

However, when discussing new service providers, participants with long-term conditions had concerns about fragmentation and poor transfer of information.

Your GP knows what's wrong with you, and they could organise your treatment much better than if you have to wait for somebody in a separate organisation.

If a minor ailment is irrelevant to my illness, it would be acceptable for me to see anybody. But I don't see how anybody can prescribe me any treatment without access to my medical records to ensure there are no drug interactions.

Expert choosers

Many participants with long-term conditions voiced the same frustrations and worries as other participants about gaining access to see a doctor, or finding necessary information to choose between hospital clinics. However, a significant minority described a higher level of choosing ability. They had learned more about their condition over time, found additional support mechanisms and developed skills at negotiating with their doctors:

It depends what your condition is, how long you have had it for and how much you know about it, as well as whether you have access to the internet and are able to research, understand and analyse what's going on. The longer you've had a condition, the more you find out about it. If when you first found out you had something you were given a choice of five different people, and were told you had to make the decision, that would be scary.

I am generally more informed about my specific condition than the general public are. If you have had a condition for a long time and are more knowledgeable about it, you are less likely to be confused and overwhelmed.

Three years ago I just went blindly to the GP. He told me the way forward and I just said, 'OK fine'. I completely trusted him and the team. Now, I would never do that again.

Several participants with long-term conditions reported using national charities as sources of information and advice:

I work for the Cystic Fibrosis Trust, and they have a database of all the clinics, regional and specialised clinics across the UK, with a table which compares the levels of treatments, so people can choose clinics that provide a certain standard of care. People do contact us to ask for information and advice as to where in their region is the best place to have treatment, because they want the best treatment for themselves.

One participant, with a rare bone problem, had explored treatment options in great detail, using scientific journals, professional websites and other sources of information to identify and assess treatment options. However, obtaining such a wide range of information can create its own problems, as there are rarely clear answers about what intervention is needed.

With my condition, there are quite a few surgical approaches. I'd have to spend years looking at the various websites for information and details about trials. Often, that information is only available to subscribers to those sites – doctors, who pay – and you can't actually see the results of the research. One team will say that its approach is best, then another will disagree. So, in some ways, it is like buying a new car where the salesmen all say different things. You have no means of independently verifying who is telling the truth. There are no statistics available to the general public.

Despite good evidence that some participants with long-term conditions had developed a wide range of skills to support choice, one participant who was very well informed about his condition, and fully engaged in choosing between treatments, expressed the need for flexibility:

It's not 'one size fits all'. Sometimes you want the choice and other times you don't feel you are able to make a choice.

Direct access to specialists

The views presented in this section illustrate some of the ways in which participants with long-term conditions had secured direct access to specialists, but this is not always available. Several had experienced delayed diagnoses because their GP lacked knowledge or experience about their problem.

If I had had direct access, I think I would have been diagnosed ten years earlier, and I would not have been suffering like I am now, because they would have recognised it much earlier and stopped it getting worse. As a result, I am much more limited in what I can do. I like the idea that you can go to your GP first, but that if they do put up a barrier there is somewhere else you can go.

Some had already negotiated direct access to specialist advice and opinion. They had developed direct links with the one or more members of their hospital team that enabled them to bypass the GP when they needed advice or care, stressing the need for specialist opinion:

I go straight to my consultant, but that's because I have regular appointments and they say, 'Phone within so many months if you want an appointment'. There is no point going to my GP.

The access to specialist opinion may not be immediate but nevertheless appeared to be valued:

If I can't get hold of my consultant by phone, I'll write a letter and I do get a response to that. You can't just walk in whenever you feel like it.

One participant in the carers' group expressed frustration at not having been able to set up immediate access in this way. Having been seen once by a consultant, the participant was told that a further appointment at a later date was not possible without a new GP referral:

It's difficult getting back to the specialist once you have seen them. I was very, very impressed with the initial way that they dealt with me, but now the difficulty is to try and get back.

For the small number of participants with rare and complex long-term conditions, easy and timely access to a specialist was particularly important because the GP knew little about their condition. One participant, with cystic fibrosis, felt that her usual GP was not the obvious choice for some relatively straightforward complaints. Fears about drug interactions and failure to recognise subtle signs of deterioration kept her in touch with their specialist hospital team:

Even my GP doesn't really know anything about cystic fibrosis, and even he can't give me advice. He says, 'Can't you just go to your clinic?' because he doesn't have expert knowledge.

Discussion

This report presents the main findings from a small qualitative study of general public view on choices in health and health care. The views, gathered from a diverse, nationwide sample of the general public offer insights that will be tested in a large quantitative survey. They highlight levels of awareness of choice and raise questions about people's desire and readiness for choice.

Attitudes to choice varied widely. Some participants were fairly sceptical about the constraints on choice, and others were worried about the impact of choice on the NHS as a whole – a finding that was consistent with the results of other studies (MORI 2003). However, the majority of participants were positive about increased opportunities for choice. A minority had personal experience of choosing between different providers, and a significant number had actively chosen between different treatments.

Initially during the discussions there was often denial that choices existed. However, after participants were prompted and encouraged to see their everyday decisions about health and health care as 'choice', many acknowledged that they did already make such choices. The findings were consistent with previous reports that not all members of the public are ready for choice and that some do not want choice but want to improve current services. This suggests it will take some time to harvest the opportunities that increasing choice provides.

The focus groups also highlighted significant frustrations about factors that constrain choice that are features of some current services. For example, there were repeated complaints that inadequate access to general practice undermines choice. There was significant limitation of available options – particularly in out-of-hours services – for those without a car, and frustration at the near-impossibility of receiving a home visit. In addition, there were concerns that resource constraints were restricting the range of choices being offered to patients. These problems may restrict the patient's ability to exercise choice to such an extent that they may undermine efforts to drive service improvements through choice.

In contrast to these structural barriers to choice were the numerous participants arguing that increasing direct access to different services would stoke demand. The comments were made primarily in response to direct access to primary care and specialist services, and highlight an inherent tension in individual attitudes. Many of the participants who cautioned that increasing direct access would trigger frivolous attendances and fuel hypochondriasis also welcomed the possibility of quick and convenient access to new primary care providers for their own minor ailments. Furthermore, while many participants

felt that direct access to specialists could be unnecessary and confusing, and would be better managed by GPs, some of those with long-term conditions had individually negotiated direct access to specialist opinion and valued this highly.

These observations raised interesting questions in relation to three areas of current policy debate:

- services outside hospital
- use of direct payments
- services for long-term conditions.

Each of these is described below.

Services outside hospital

The first point to note is the implications of the participants' observations for the forthcoming White Paper on health care outside hospitals. Several factors are driving the development of care outside hospitals – among them, the extension of market-style incentives into primary care in an attempt to improve responsiveness and efficiency. Specialist primary medical services (PMS) and advanced primary medical services (APMS) offer a mechanism through which new providers can enter the primary care market to provide primary care services in pockets of unmet need, or where local delivery through traditional NHS bodies is failing, either in terms of cost or quality (National Association of Primary Care 2004).

With the stage set for new providers to transform the style and location of primary care services, and evidence that an array of commercial organisations are getting ready to do so (Craig and Feast 2005), findings from these focus groups require careful consideration. Inadequate access to primary care is a source of frustration and dissatisfaction, and there is clearly a need to address this issue. Yet evidence from NHS Direct and walk-in centres reveals that these new direct-access services have generated additional demand rather than being substituted for other services (Hsu *et al* 2003, Kmietowicz 2005). Findings from the focus groups suggest that a similar pattern could occur if access to primary care is made easier, unless some form of demand management is also developed. The view was widely held that easier access would fuel demand for advice on minor problems. Demand management mechanisms will be required as part of the changing landscape of out-of-hospital care.

Yet it is hard to see how to achieve this. The incentives that aim to improve responsiveness through a more competitive primary care market may also encourage supplier-induced demand. It remains to be seen whether practice-based commissioning – envisaged as a restraining influence on demand for hospital care – can have a similar effect on out-of-hospital services. Nor is it clear that such restraint would always be desirable. For example, enhancing access to services for monitoring long-term conditions and improving uptake is a current policy aim, to which participants in emerging primary care market may contribute. It remains to be seen how 'demand' for such services will influence their development and use, and what effects it will have on costs.

Use of direct payments

The focus groups generated interesting data on direct payments as a mechanism for exercising choice about health care. Despite confusion among some participants about the idea of direct payments, including some concerns that patients would have to make personal out-of-pocket contributions, there was nevertheless some support for the use of direct payments for health care. In relation to payments for selected therapies (such as chiropody or physiotherapy), people saw the potential for obtaining flexibility from service providers. There was a willingness to tolerate the use of vouchers for alternative therapists if that was what somebody wanted to choose.

Many participants were willing to accept the notion of top-up payments being used to buy a 'deluxe' service for those who could afford it. There was also widespread recognition of the need to regulate services and ensure standards, along with some concerns about how individuals could do that.

Pursuing the idea of direct payments into the more complex areas of managing long-term conditions and whole (annual) packages of care left many participants confused. Yet some understood these options, and saw advantages and disadvantages associated with them. The main advantage identified for disease management programmes was considered to be the possibility to receive care from a specialist provider with a more in-depth and up-to-date knowledge than a generalist could be expected to maintain. Among the main concerns were: the complexity of obtaining information about such providers and of making judgements about whether they were good; differing views about the desirability of regular phone contact; and the problems of fragmentation and duplication. The latter issues were voiced particularly by people with two or more conditions.

With an emerging market in health care provision, several companies with an interest in disease management, and use of direct payments for health care under discussion, these observations provide some insights to inform future policy in this area.

Discussion about direct payment for whole packages of care is particularly relevant to contemporary questions about how to stimulate improvements in commissioning. Though not actively under consideration in Nigel Crisp's letter to the NHS 'Commissioning a Patient-led NHS' (Department of Health 2005b), it could be argued that competition between primary care trusts (PCTs) would stimulate improvements in commissioning akin to the impact of competition for enrollees seen in managed care organisations in the USA (Dixon *et al* 2004).

One could equate use of such vouchers to buying an annual insurance package – an idea that met with a mixed, but largely negative response. Familiar comments about difficulties in accessing information were made, and for some the complexity of such an important decision seemed too much, but the approach was not universally rejected.

Services for long-term conditions

Participants with long-term conditions had many views in line with other participants, but some differences became apparent. They clearly valued continuity of relationship with both GPs and practice nurses, but also valued the benefits of rapid access to specialists. These were described as: reducing the risk of missed or delayed diagnosis; supporting

people in the ongoing management of their condition; and bypassing the under-informed generalist when managing acute problems (for those with rare or complex conditions).

With missed and delayed diagnosis of long-term conditions being a widely recognised problem (Royal College of General Practitioners/National Patient Safety Agency), and with the need to improve access to timely diagnosis sitting at the top of a list of improvements pursued by patient groups (Partnership on Long Term Conditions 2004), the plea by one focus group participant to be able to bypass the GP after three or four visits without a satisfactory resolution raises interesting questions.

The effects of limited access to diagnostic services on delayed diagnosis are now being addressed through a national diagnostics procurement programme from independent sector providers. The national target of a maximum 18-week wait from referral to completed investigation and treatment by 2008 (HM Treasury 2002) will also improve timely diagnosis so long as a referral is made by the GP. However, the possibility of allowing direct access to a specialist for those whose GP is not willing – after several consultations – to refer to a specialist is an interesting one.

For those with an established diagnosis, many described being able to contact either a nurse specialist or a consultant when they ran into problems. Participants with common conditions, such as asthma and diabetes, typically (but not exclusively) contacted a GP or specialist practice nurse. Others had secured direct access by phone or email to a hospital specialist. All who commented regarded this type of expert opinion as an important alternative to contacting a generalist with insufficient understanding of their condition. For those with severe conditions, this was an essential way to avoid serious complications.

While such arrangements are increasingly common, they are not universal – as revealed by the frustrated carer who could not re-gain access to a hospital consultant without being referred by their GP again. A recent study of self-management identified flexible arrangements for contacting specialists as being highly valued by patients and increasingly possible through email and phone contact (Corben and Rosen 2005). As PCTs review their services for long-term conditions, the value that patients attribute to specialist access should stimulate a review of how this could happen within local health economies.

The focus groups illustrate that choice between providers is as relevant and welcome for people living with long-term conditions as for those who are unaffected by chronic illness. But current initiatives to extend choice only partially address their needs. The emerging market in primary care will have to support continuity and trusting relationships between patients and clinicians if it is to respond to the needs of this group. Furthermore, as people develop knowledge and expertise about their conditions and the treatments that exist, policies that restrict access to selected interventions on the basis of cost or effectiveness may be seen to make choice a ‘chimera’ for those with serious and long-term conditions. And for those with serious and rare conditions, for whom specialists rather than generalists have the necessary skills and knowledge to manage clinical problems, opportunities to choose direct access to specialist advice are valued. It will be important to address these issues when further developing policies on choice.

Future work on choice

As a follow-up to this piece of research, a further quantitative study is underway. This next stage will build on themes identified in the focus group analysis in order to identify key issues that can be assessed quantitatively. The aim of this is to quantify:

- public preferences about choice
- attitudes towards diversity in provision of primary care
- attitude to choices among people with long-term conditions
- trade-offs people make in choices about health and health care.

The research will be undertaken using a questionnaire survey of 1000 people with a boost sample of 500 people living with a long-term condition.

References

- Appleby A (2003). 'Patient choice in the NHS'. *British Medical Journal* vol 329, pp 61–2.
- Harrison A, Devlin N (year?). *What is the Real Cost of More Patient Choice?* London: King's Fund.
- National Centre for Social Research. *British Social Attitudes Survey* (in press)
- Appleby J, Harrison A (2005). *The War on Waiting for Hospital Treatment: What has Labour achieved and what challenges remain?* London: King's Fund.
- Burge P, Devlin N, Appleby J, Rohr C, Grant J (2005). *London Patient Choice Project Evaluation*. London: RAND Corporation/City University/King's Fund.
- Corben S, Rosen R (2005). *Self Management for Long-term Conditions*. London: King's Fund.
- Craig G, Feast S (2005). 'A new environment for primary care'. *The Pharmaceutical Journal*, vol 274, 7353, p 709.
- Damiani M, Dixon J, Propper C (2005). 'Mapping choice in the NHS: cross sectional study of routinely collected data'. *British Medical Journal*, vol 330: 7486, pp 284–7.
- Dash P (2004). 'New providers in UK health care'. *British Medical Journal*, vol 328, pp 340–2.
- Department of Health (2002a). 'A new role for overseas and independent healthcare providers in England'. Press release 2002/0283. London: Department of Health.
- Department of Health (2002b). *Reforming NHS Financial Flows: Introducing payment by results*. London: Department of Health.
- Department of Health (2003). *Building on the Best: Choice, responsiveness and equity in the NHS*. London: The Stationery Office.
- Department of Health (2004a). *Autumn Performance Report 2004*. London: The Stationery Office.
- Department of Health (2004b). *Choose and Book: Patient's choice of hospital and booked appointments*. London: Department of Health.
- Department of Health (2004c). *Choosing Health: Making healthier choices easier*. London: The Stationery Office.
- Department of Health (2004d). *The NHS Improvement Plan: Putting people at the heart of public services*. Cmnd 6268. London: The Stationery Office.
- Department of Health (2004e). *Sustaining Innovation Through New Primary Medical Services Arrangements*. London: Department of Health.
- Department of Health (2005a). *Chief Executive's Report to the NHS*. London: Department of Health.

Department of Health (2005b). 'Commissioning a Patient Led NHS'. Letter from Sir Nigel Crisp to the NHS. Gateway reference 5312.

Department of Health (2005c). *Contractual Framework for Community Pharmacy*. London: Department of Health.

Department of Health (2005d). *Self Care – A Real Choice: Self care support – a practical option*. London: Department of Health.

Department of Health (2005e). *Supporting People with Long Term Conditions. An NHS and Social Care Model to support local innovation and integration*. London: Department of Health.

Department of Health (2005f). *Treatment Centres: Delivering faster, quality care and choice for NHS patients*. London: Department of Health.

Dixon J, Lewis R, Rosen R, Grey D, Finlayson B (2004). *Managing Chronic Disease: What can we learn from the US experience?* London: King's Fund.

HM Treasury (2002). *Public Services Performance Index*. London: HM Treasury.

Harding ML (2005). 'You choose: new forces to be reckoned with in primary care'. *Health Service Journal*, vol 115, no 5967, pp 14–15.

Hsu R, Lambert P, Dixon-Woods M, Kurinczuk J (2003). 'Effect of NHS walk-in centre on local primary healthcare services: before and after observational study'. *British Medical Journal*, vol 326: 7388, p 530.

Kmietowicz Z (2005). 'Walk-in centres fail to take pressure off emergency services in England'. *British Medical Journal*, vol 330, p 745.

Labour Party, The (2005). *Britain Forward not Back: The Labour Party manifesto 2005*. London: The Labour Party.

MORI (2003). *Patient Choice in Birmingham, Solihull and the Black Country*. Research Study conducted for Birmingham and the Black Country Strategic Health Authority. London: MORI.

National Association of Primary Care (2004). *Examination of Specialist PMS (SPMS)*. London: National Association of Primary Care.

National Audit Office (2005). *Patient Choice at the Point of GP Referral*. London: National Audit Office.

Partnership on Long Term Conditions (2004). *17 Million Reasons: Improving the lives of people with long term conditions*. London: Partnership on Long Term Conditions.

Riddell S, Pearson C, Barnes C, Jolly D, Mercer G, Priestley M (2005). 'The development of direct payments in the UK: implications for social justice'. *Social Policy and Society* 4(1), pp 75–85.

Royal College of General Practitioners/National Patient Safety Agency. *In Safer Hands: Missed and delayed diagnosis*. www.rcgp.org.uk/quality_unit/insaferhands/ISH6.pdf (Accessed 20 September 2005)

Worcester R (2003). *Patient Choice*. London: MORI/London School of Economics.

Linked publications

Self-management for long-term conditions: Patients' perspectives on the way ahead

Sara Corben, Rebecca Rosen

Millions of people in the UK are living with long-term conditions such as asthma or diabetes. Most of these people are leading full and active lives with only occasional contact with health professionals, by altering drug doses and adapting their lifestyles in response to subtle changes in symptoms. This paper reviews patients' perceptions about managing their own conditions, and identifies how primary care trusts and other health and social care providers can support them, in line with their individual needs. Three key areas for service development are:

- improving health professionals' skills to help patients manage their own conditions
- improving the provision of information about long-term conditions and the local services available
- increasing the flexibility of services to fit in with patients' other commitments.

July 2005 ISBN 1 85717 498 4 21 pages £5.00

[Download in full](#)

Managing Chronic Disease: What can we learn from the US experience?

Jennifer Dixon, Richard Lewis, Rebecca Rosen, Belinda Finlayson, Diane Gray

As the UK population ages, growing numbers of patients will need help with managing complex, multiple conditions over sustained periods. This will pose significant challenges for the NHS, which will face both a large burden of ill-health and vastly increased costs. This paper looks at evidence from the United States that it is possible for the NHS to improve its management of chronic conditions. It gives a critical analysis of five managed care organisations across the United States – all among the top performers in the care of people with chronic conditions – and asks what lessons or transferable models might emerge for health care in England.

January 2004 ISBN 1 85717 476 3 54 pages £8.00

[Download summary](#)

What is the Real Cost of More Patient Choice?

John Appleby, Anthony Harrison, Nancy Devlin

At first glance, an increase in patient choice seems to be unequivocally 'a good thing'. But what trade-offs are really involved – and what price are we prepared to pay? And how far can individual freedoms be extended while retaining the essential objectives of the NHS? This discussion paper sets out the questions that the government needs to answer if it wants to place patient choice at the heart of a health care system funded by taxpayers. These include how extra costs will be met, whether patients are willing and able to exercise choice in their own best interests, and what kinds of limits to choice might be needed.

June 2003 ISBN 1 85717 473 9 64 pages £6.50

[Download in full](#)

Changing Relationships: Findings from the patient involvement project

Rosemary Gillespie, Dominique Florin, Steve Gillam

Patient-centred care is an accepted approach within health care, but what does it really mean? This publication looks at how policy has shifted in response to wider cultural changes and high-profile investigations such as the Bristol inquiry, which found doctors at the Bristol Royal Infirmary guilty of serious professional misconduct. Drawing on the results of interviews with a wide range of clinicians and stakeholders, it reveals widespread disparities in understandings of patient-centred care and how to achieve it, and highlights a tendency to redefine existing activities to fit the concept of patient-centred care. The paper suggests that patients, users and carers must play a key role in determining what patient-centred care means, and should be given more power and control, if clinical encounters are to become truly patient-centred.

October 2002 ISBN 1 85717 468 2 32 pages £6.00

Download in full

Producing Patient Information: How to research, develop and produce effective information resources

Mark Duman

Patients need information from health providers to be clear, appropriate and timely, to help them understand their situation, grasp what they need to do, and make informed decisions. But often health information is not suitable or accessible to its audience.

The updated second edition of this guide is designed to support a wide range of health professionals in the public, commercial and voluntary sectors to develop the quality and impact of the information they produce. With a foreword by Harry Cayton, National Director for Patients and Public, Department of Health, this edition has been fully updated in line with the latest developments in new media such as CD ROMs and the internet. The guide also shows how to use traditional media, such as print, to the best advantage.

September 2005 ISBN 1 85717 470 4 128 pages £25.00

To order any of these titles, and to discover our full range of publications on health and social care, visit our online bookshop at www.kingsfund.org.uk/publications, or call Sales and Information on 020 7307 2591.