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Patients' experience of choosing where to undergo surgical treatment

EVALUATION OF LONDON PATIENT CHOICE SCHEME

Angela Coulter, PhD
Chief Executive

Naomi le Maistre, MA
Research Officer

Lorna Henderson, MSC
Research Officer

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CONTENTS

Executive summary

1. London Patient Choice (LPC) offered patients facing a wait of more than eight months for elective surgery the option of going to an alternative London provider that could offer faster treatment. This study, part of a wider evaluation of LPC, focused on patients' experience of the scheme.

2. The study had four main aims: to explore patients' reactions to the offer of hospital choice and to determine which factors influenced their decisions on where to have their treatment; to compare uptake between different social groups; to identify patients' requirements for information and practical support; and to compare the experiences of those treated at their home hospitals and those who opted to go elsewhere for their surgery.

3. Patients from five originating trusts (OTs) were sent postal questionnaires before they had been offered a choice of hospital and after they had been discharged from hospital. In-depth interviews were carried out with a sub-sample in each group. A record review was carried out to determine rates of acceptance of the offer of an alternative hospital.

4. Completed questionnaires were received from 2,144 out of 3,988 patients sent the *Before Surgery* questionnaire (response rate 54%) and from 977 out of 1,839 sent the *After Surgery* questionnaire (response rate 53%). In addition 27 interviews were conducted with patients awaiting surgery and 24 with patients who had completed treatment and their carers.

5. Most of those surveyed while on the waiting list (82%) responded positively when asked if they would consider going to an alternative hospital. Only 18% said they would not consider it under any circumstances. People in paid employment, those with higher education and those with above average household incomes were somewhat more likely to be willing to consider it than those in the other social groups.

6. When considering where to be treated, patients had to weigh up various factors, including the perceived urgency of treatment, the likely quality of care in different hospitals and the facilities they could offer, as well as practical considerations such as transport arrangements, timing of treatment and convenience for themselves and their relatives. Practical considerations tended to weigh more heavily for those in less advantaged groups.

7. Less than a third (32%) of patients apparently eligible for the scheme were actually offered a choice of hospital. This low rate of offer was surprising and the reasons for it are unclear. There was significant variation between the OTs in the proportion of patients offered a choice, ranging from 14% to 42%.

8. Two-thirds (67%) of those who were offered the opportunity to go to an alternative hospital chose to do so. We found no evidence of inequalities in access to, or uptake of alternative hospitals by social class, educational attainment, income or ethnic

group, but people in paid employment were more likely to opt for an alternative hospital than those not in paid employment.

9. Uptake was also influenced by the level of pain experienced while on the waiting list and by patients' views of the reputation of their home hospital. Those in more pain and those who felt their home hospital had a fair or poor reputation were significantly more likely to choose to undergo treatment elsewhere.

10. Most patients who opted for an alternative hospital were treated in NHS treatment centres (82%). Others went to other NHS hospitals in London (13%) or private hospitals (5%). Only one patient in the study received treatment at an overseas hospital.

11. The support received from patient care advisors (PCAs) was highly regarded by patients. Their role in guiding patients through the process, helping them to make a decision, and coordinating arrangements between the hospitals was particularly appreciated by those who opted to go to an alternative hospital.

12. When deciding where to undergo treatment patients tended to place greatest emphasis on issues such as where the hospital was located, length of wait for the operation, travel arrangements and convenience for family and friends.

13. One in three survey respondents expressed dissatisfaction with the amount of information received about the different hospitals. In particular patients wanted more information about arrangements for follow-up care, quality of care, qualification and experience of surgeons, operation success rates, standards of hygiene and safety record.

14. The provision of free transport was a popular aspect of the scheme attracting high satisfaction ratings.

15. Patients treated at alternative hospitals were significantly more satisfied with their hospital experience than those treated at their home hospital. Patients who had their operations in specially designated treatment centres or private hospitals were more positive about their experience than those whose surgery took place in an ordinary NHS surgical department.

16. There were no significant differences between the groups in their evaluation of the follow-up care received. Patients treated at home hospitals and those treated at alternative hospitals were equally satisfied with this aspect of their care, but one third in each group would have liked more follow-up.

17. An overwhelming majority (97%) of patients who had opted to go to an alternative hospital said they would recommend the scheme to others.

18. The LPC scheme achieved its main objective in relation to the provision of faster access to good quality care, which was for the most part well-coordinated and responsive. The main problem, as far as patients were concerned, was the failure to provide sufficient information about quality and performance in the various alternative providers to enable fully informed decision-making.

19. Rates of uptake in this study do not provide a reliable guide to the likely demand for alternative providers when the national scheme, offering choice at six months and/or choice at the point of referral, is rolled out. The new *Choose and Book* scheme will be different from the model piloted in London and uptake is likely to be affected by various factors, including reasons for referral, prevailing waiting times, travel arrangements, public awareness of quality standards at different facilities, and perceptions of providers' reputations.

20. Market incentives will only help to drive up quality standards if patients are able to act as discerning consumers. To enable them to discriminate between different providers, they and their GPs will require reliable unbiased information about quality standards. Dedicated treatment centres, agreed patient care pathways and coordination across service boundaries are key elements of a high quality service for patients undergoing elective surgical procedures.

21. If all patients throughout the country are to have an equal opportunity to make choices about where and when they are referred, they must be made aware of their rights in this regard, adequate information and support must be available, and monitoring systems must be put in place to avoid risk of discrimination against less advantaged groups.

1 Introduction

London Patient Choice (LPC) was part of a commitment in the NHS Plan to give patients more choice. Established in 2002, it was one of nine pilot projects designed to test the feasibility of giving patients awaiting elective surgery a choice of where to undergo their operation. It also addressed another of the government's priorities for the NHS, namely the reduction of waiting times. By offering patients facing a long wait for surgery the option of going to an alternative provider, it was hoped that the incidence of long waiting times would be reduced. The scheme targeted patients waiting for admission to an NHS Trust in London where waiting times were likely to be eight months or more. These patients were given an opportunity to go to a hospital that could offer earlier treatment, including other NHS trusts in London with spare capacity, specially designated treatment centres specialising in particular types of elective surgery, private hospitals or, in certain cases, hospitals overseas.

The LPC evaluation has three strands: a group based at Royal Holloway and Imperial College have addressed the **management and implementation** of the scheme; the **system-wide impacts** have been examined by a research group based at the University of York, while researchers at Picker Institute Europe focused on **patients' experience** of the scheme, the subject of this report.

The research team at Picker Institute Europe was commissioned by the Department of Health to examine patients' experience of the scheme and to develop a predictive model of future uptake, based on an understanding of the factors that influence patients' decisions. The modelling exercise was sub-contracted to a team at RAND Europe and the King's Fund and is the subject of a separate report.

1.1 Policy context

The LPC scheme commenced in October 2002, when the option of earlier treatment at an alternative hospital was offered to patients waiting for cataract operations. This was subsequently extended to patients waiting for elective surgery in other surgical specialties. Offering patients more choice was seen as an important method of empowering service users and raising quality standards while at the same time helping to bring down waiting times.

Choice is dependent on the availability of beds and staff, so providers were encouraged to expand capacity and improve the management of existing resources to enable patients to exercise choice. Funds were made available for this purpose and several treatment centres specialising in elective surgical procedures (e.g. hip and knee replacements or cataract operations) were established. The hospital choice schemes were predicated on the assumption that some patients would be willing to travel to more distant hospitals where waiting times were shorter. Money would follow the patient, so hospitals would have an incentive to improve the quality of their services to attract them. It was hoped

that this would lead to more efficient use of resources by providing a structured way of moving excess demand to areas of new supply.

Historically patient choice has been constrained in the NHS, but there is evidence that many patients feel they should be able to choose who to consult or where and when to be treated. A recent study carried out among random population samples in eight European countries, including the UK, found strong support for the notion of free choice of provider: 92% wanted to be able to choose their primary care doctor, 85% wanted to be able to choose which specialist to see, and 86% wanted a free choice of hospital[1]. British people were among the most dissatisfied with the opportunities for making healthcare choices in their country, with only 30% saying that these were 'good' or 'very good', compared to 73% in Spain and 70% in Switzerland.

A MORI poll conducted in August 2003 confirmed this pessimism about the possibility of choice in the NHS. More than a third (38%) of those interviewed said that NHS patients currently do not have any choices and a further third said they didn't know what choices they could have. But when asked which choices should be available, two-thirds (66%) said they felt NHS patients should be able to choose where to have their operations[2].

So, on the face of it, the introduction of hospital choice would appear to be a well-timed attempt to make the system more responsive to patients' preferences. More choice for patients coupled with explicit standards, external review and inspection, should, according to the government, achieve the desired balance of more responsive, flexible and high quality care for all. But despite the generally positive public attitudes towards choice, there were also concerns about potential adverse effects, in particular that better-off people would be best equipped to take advantage of choice, leaving those in deprived groups with very little choice. This might lead to greater inequalities in access to care and perhaps worse quality of care for those with greatest need.

While healthcare in the UK is distributed more equitably than in many OECD countries, a measure of inequality in access to care has always existed. For example, a recent study found that deprived individuals and families used the health service less than their levels of need would indicate they should.[3] These included inequalities in gaining access to elective surgical procedures, such as cardiac surgery, hernia repair, cholecystectomy, tonsillectomy and hip replacements. The researchers postulated that barriers to access for these groups may include travel costs, job constraints, communication problems and low levels of health literacy. Critics of the hospital choice schemes have claimed that they pander to a middle class agenda and will benefit only those for whom these barriers do not exist. These critics argue that, instead of offering choice to those limited few who might benefit from it, greater priority should be accorded to improving all services used by disadvantaged groups.

However, the government has claimed that greater inequity is not an inevitable consequence of increased choice.[4] On the contrary, the hope is that targeted support for

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1 Coulter A, Magee H. *The European Patient of the Future.* Maidenhead: Open University Press, 2003

2 MORI. *Patient Choice.* Study conducted for BUPA Health Debate 2003.

3 Dixon A, Le Grand J, Henderson J, Murray R, Poteliakhoff E. *Is the NHS Equitable? A review of the evidence.* LSE Health and Social Care Discussion Paper 11. London School of Economics and Political Science, 2003

4 Secretary of State for Health. *Building on the best: choice, responsiveness and equity in the NHS.* Cm. 6079. London: Department of Health, 2003

poorer people will give them some of the same choices that are currently available to middle class people, for example by putting pressure on the low quality providers that people from disadvantaged groups are often forced to rely on. They hope it might also help to maintain support for the NHS among the middle classes, thus ensuring sustainability of the tax-funded system.[5]

1.2 Previous research on patients' reactions to hospital choice

A number of studies have looked at patients' reactions to being given a choice of where to be treated. Most of these have focused on the types of trade-offs involved in these decisions. The decision about whether or not to opt for treatment at an alternative to the patient's 'home' hospital is likely to be influenced by a variety of factors. The two most obvious of these are waiting time and travelling distance. In a 'stated preference' study carried out among patients on the Isle of Wight, Ryan and colleagues focused specifically on the trade-offs people would be willing to make between these two issues.[6] They concluded that patients would be willing to travel further afield for their treatment if their waiting time was reduced by at least 3.9 months. Other factors that have been identified as being of importance to patients include convenience for friends and family, concerns about continuity of care including follow-up care, and views about, or previous experience of, their local hospital.[7,8,9,10]

All the studies of choice cited above asked hypothetical questions of patients who had not been offered a real choice. The first study to look at real-life experience of British patients offered a choice of hospital was the Picker Institute's evaluation of patients' experience of hospital choices in heart surgery (CHD Choice).[11] Uptake was high in CHD Choice, with more than half (57%) of those who were offered a choice opting to go to an alternative hospital. Younger people (under 60) were slightly more likely to be willing to travel for faster treatment (61%) than those in the older age-group (56%). More than two thirds (71%) said reputation of the hospital was a very important factor influencing their decision, followed by speed of treatment (67%), reputation of the surgeon (64%), convenience for family and friends (49%), and travelling distance (36%). The evaluation of CHD Choice concluded that the scheme was beneficial for patients who were treated more quickly and were on the whole very satisfied with the care they received. There was some scope for improvement, particularly in relation to provision of information, travel arrangements and aftercare, but the scheme achieved its main objectives, at least as far as the patients were concerned.

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5 Stevens S. Equity and choice: can the NHS offer both? In: Oliver A (ed) *Equity in health and healthcare*. London: Nuffield Trust, 2003

6 Ryan M, McIntosh E, Dean T, Old P. Trade-offs between location and waiting times in the provision of health care: the case of elective surgery on the Isle of Wight. *Journal of Public Health Medicine* 2000; 22: 202-210

7 MORI. *Patient choice in the NHS. London:* MORI, 2001

8 Rigge M. *Headlines from qualitative and quantitative analysis of replies to College of Health telephone survey on patient choice in the NHS.* London: College of Health, 2001

9 BPCA: *Patient choice and waiting*. London: British Cardiac Patients Association

10 Silkap Consultants. *Real choice: factors influencing user and carer uptake of 'Choice' in London*. London: NHS Executive/Silkap Consultants

11 Le Maistre N, Reeves R, Coulter A. *Patients' experience of CHD Choice.* Oxford: Picker Institute Europe, 2003

1.3 Design of London Patient Choice

LPC differed from CHD Choice in that it catered for patients across a range of specialties with a variety of conditions, and it was confined to one geographical area, albeit a very large one. The project was coordinated by a central project group, the LPCP team, who planned and supervised its implementation.

NHS Trusts in London with significant numbers of patients waiting more than six months for elective surgery, referred to as Originating Trusts (OTs), were paired up with other London providers (NHS or private) that had spare capacity or with one of the new treatment centres. These were known as Receiving Trusts (RTs), although they included independently-run treatment centres and private hospitals as well as other NHS Trusts. Each OT was paired up with at least two RTs that could offer faster treatment to patients on their waiting lists who met the eligibility criteria. These 'buddy' arrangements between hospitals were facilitated by the LPCP team.

Initially the scheme was restricted to patients awaiting cataract surgery, but it was later extended to include patients awaiting specific procedures in ear, nose and throat surgery (ENT), general surgery, ophthalmology, orthopaedics, and urology (Table 1). Gynaecology and plastic surgery were introduced on a pilot basis in the south east London only. The selected conditions or procedures in each specialty were those for which patients were most likely to have to wait more than six months. For each procedure an agreed patient care pathway was developed and agreed between OTs, RTs and the LPCP team.

The expectation was that most patients awaiting one of the specified procedures would be offered the choice of continuing to wait for treatment at their 'home' hospital (the OT) or receiving faster treatment at one of two alternative providers (RTs). In certain cases patients might be offered the option of treatment at a hospital overseas.[12] Patients would be excluded from the scheme if their OT could guarantee them treatment within eight months of going on the waiting list (later reduced to seven months), or if there were agreed clinical reasons why treatment at an alternative provider was considered inappropriate. Clinical exclusion criteria were specified by the LPCP team after wide consultation with clinicians in the relevant specialties in both OTs and RTs and after reviewing the literature to determine best practice.

12 The overseas treatment programme was restricted to four trusts only and operated on behalf of LPC by a team from Guy's and St. Thomas's NHS Trust. Under this scheme some patients awaiting hip or knee replacement underwent surgery in hospitals in Belgium. The small number of patients selected for this scheme had to be sufficiently fit to travel to Belgium on the Eurostar trains.

Table 1: London Patient Choice eligibility and exclusion criteria

Specialty	Procedures	Eligible patients	Exclusion criteria
General surgery	Hernia repair Cholecystectomy Varicose veins Haemorrhoids Pilonidal sinus	All patients who have been on the waiting list for the agreed procedures for 5 months and 2 weeks and are registered with a London GP	Known MRSA; pregnant; age under 16 years; ASA 4 or 5 (if known); taking warfarin (if known)
Orthopaedics	Hip replacement Knee replacement Knee arthroscopy	All patients who have been on the waiting list for the agreed procedures for 5 months and 2 weeks and are registered with a London GP	Known MRSA; MI or cardiac surgery within last 6 months; pregnant; under 16 years; current renal dialysis
Opthalmology	Cataract or other eye operation	All patients who have been on the waiting list for the agreed procedures for 5 months and 2 weeks and are registered with a London GP	No specific exclusion criteria
ENT	Ear/nasal surgery Tonsillectomy Adenoidectomy Grommets	All patients who have been on the waiting list for the agreed procedures for 5 months and 2 weeks and are registered with a London GP	BMI above 35 (if known); unstable diabetes (if known); unstable cardiovascular/pulmonary disease (if known); coagulopathies; haemoglobinopathies; patient is pregnant; does not comply with ASA Grades 1 and 2 (if known)
Urology	Prostatectomy Cystoscopy Vasectomy Bladder surgery Circumcision and other day case procedures	All patients who have been on the waiting list for the agreed procedures for 5 months and 2 weeks and are registered with a London GP	Known MRSA; MI or cardiac surgery within last 6 months; taking warfarin/anticoagulants (if known); current renal dialysis or ongoing complex renal treatment; patients listed for TURP who have a known malignancy

The scheme was facilitated by Patient Care Advisors (PCAs) who were independent of the OTs and RTs and who were responsible for liaising with patients throughout the process. The PCAs were employed by NHS Direct and based at a call centre in Croydon. At the point when a decision had been taken to place them on the waiting list for surgery, patients attending outpatient clinics at OTs were to be informed in general terms about the choice scheme. It was expected that patients whose medical condition was too complex to be consider a transfer of care for surgery would be identified at this point and screened out of the LPC system. Staff at OTs were responsible for validating the waiting lists and sending names of eligible patients to the PCA team. The validation process was supposed to take place when patients had been on the waiting list for around four months. If patients were considered ineligible for the scheme at this stage, staff at OTs were required to inform them of the reasons why they had been excluded.

After four months on the waiting list eligible patients were sent a letter and an information booklet outlining the scheme in more detail and giving them advance warning that a PCA would contact them by telephone to discuss their options. Eligible patients included all those registered with a London GP who had been on the waiting list for one of the specified procedures for a period of at least 22 weeks, excluding those with specific co-morbidities.

When patients reached the five-and-a-half month point on the waiting list (later reduced to four-and-a-half months) a PCA would contact them by phone or letter to offer them the option of going to an alternative hospital, to answer their questions, and to make the necessary arrangements. If the patient agreed to accept the offer of an alternative, the PCA was responsible for booking an appointment (the 'operative appointment' – a combination of a clinical validation, an outpatient appointment and a pre-operative assessment). They would offer continued telephone contact with the patient and provide support if any problems occurred. They were also responsible for keeping the patient's GP informed if their operation had been scheduled to take place at an RT. If the patient decided to accept the offer of an alternative hospital, they were given a specified date for their operation. The intention was that their treatment would be completed within eight-and-a-half months of joining the waiting list.

In the event this procedure was not followed in each of the OTs exactly as specified. For example, in some cases patients were not given the preliminary information about the scheme to avoid raising expectations amongst those subsequently deemed ineligible for the choice process. While the LCP team recommended early 'fitness for surgery' assessment, this was not common practice during the life of the project. The process of validating the waiting lists and determining eligibility also varied between Trusts (see below).

1.4 Future developments

While the evaluation of the LPC scheme was still in progress, the government announced that the hospital choice pilots had been deemed a success and the scheme was to be adapted for national roll-out. The new national scheme will evolve into a somewhat different form from the model piloted in London. In the first instance, the offer of at an alternative hospital after six months on the waiting list will be rolled-out nationwide for

patients awaiting elective surgery, along similar lines to that piloted in LPC. Then from January 2005, patients requiring cataract surgery will be offered a choice of at least two hospitals earlier on in the process, i.e. at the point when they are referred by their GP or an optometrist to a hospital specialist. Finally, from December 2005 all patients requiring specialist advice, diagnosis or treatment will be offered a choice of up to five hospitals (or suitable alternative providers) and a choice of time and date for their appointment, when their GP decides a referral is necessary.

The new system will be known as *Choose and Book*. As well as choosing which hospital to go to for diagnosis, advice or treatment, patients will be able to choose the date of their appointment or admission, making use of the new electronic booking system. Appointments and admissions will be booked via a call centre, an online booking system, or, eventually, via digital television. Primary care trusts will be responsible for ensuring that patients are offered options and the necessary systems and processes are in place to offer and support choice and to enable booked appointments to be made. Secondary care services will be responsible for ensuring that patients' requirements in relation to the timing and location of their booked appointments are met.

The government hopes that this new system will bring benefits to patients and to the NHS as a whole.[13] They argue that it will give patients more influence over the way they are treated and will ensure a more personalised service. The stress of the referral process will be reduced because patients will know with more certainty when their treatment is due. Having a choice of time and place should enable them to fit their treatment in with their life, not the other way round. Meanwhile, it is hoped that the streamlined system will reduce the administrative burden for the service and lead to fewer appointments cancelled due to non-attendance by patients and/or health professionals.

The implications of our findings for this new national system are considered in chapter 10 of this report.

13 Department of Health. *"Choose & Book" – Patient's Choice of Hospital and Booked Appointment*. London: Department of Health, 2004

2 Study aims and methods

2.1 Aims

The evaluation of patients' experience of the LPC had four main aims:

- To explore patients' reactions to the offer of hospital choice and to determine which factors influenced their decisions on where to have their treatment;
- To compare uptake of choice (i.e. willingness of patients to travel to an alternative hospital) between different social groups;
- To identify patients' requirements for information and practical support when making a decision about where to undergo surgery;
- To compare the experiences of those patients treated at their 'home' hospitals and those who opted to go elsewhere for their surgery.

The study was commissioned and funded by the Department of Health. Approval to carry out the study was obtained from the Multi-Centre Research Ethics committee for Scotland (MREC reference 02/10/23).

2.2 Methods

Consecutive patients were surveyed to elicit their reactions to the choice process and their subsequent health care experience. They were also asked to participate in a discrete choice experiment, designed by researchers at RAND Europe and the King's Fund, to explore their reactions to varying hypothetical healthcare providers, with different localities, travel distances, and sectors (i.e. public versus private). The discrete choice experiment was embedded in the *Before Surgery* questionnaire (see below). The results of this experiment are detailed in a separate report (Burge et al 2004).

Patients were mailed self-completion questionnaires at two points: first while they were on a waiting list for surgery (the *Before Surgery* questionnaire), and then after they had received their treatment (the *After Surgery* questionnaire). All study participants received at least one of the questionnaires, and a subset, hereafter referred to as the cohort group, completed both the *Before Surgery* and the *After Surgery* questionnaires. In addition, in-depth interviews were carried out with a smaller sample of patients before and after surgery and with their carers. See the Appendix (p. 75) for further details on the development and pilot-testing of the questionnaires.

The use of two cross-sectional surveys and a smaller longitudinal cohort was necessary because of the limited study time available compared to the time it took for patients to flow through the system. Originally we had hoped to recruit a larger cohort group, but problems involved in obtaining the participation of Trusts meant the data collection period had to be compressed (see Appendix).

There were therefore three main study groups and two sub-samples:

- Before surgery – questionnaire and interview (Groups A_1 and A_2)
- After surgery – questionnaire and interview (Groups B_1 and B_2)
- Cohort - completed both questionnaires (Group C)

In order to obtain outcome data for Group A we undertook a review of LPC records to determine which patients had decided to opt to go to an alternative hospital (record review).

Data collection took place in five distinct phases:

1. Pilot work and before surgery interviews (January 2003 – August 2003)
2. Before surgery survey (September 2003 to January 2004)
3. After surgery survey (February 2004 to April 2004)
4. After surgery interviews (March 2004 – June 2004)
5. After surgery record review (July 2004)

Following consultation with the LPC coordinating team, five OTs were approached with a request to participate in the evaluation. The OTs, which were located in four sectors of the London region, were selected because they were likely to export sufficient numbers of patients to achieve the required sample size. They were as follows:

- Barking, Havering and Redbridge NHS Trust (north-east sector)
- Barnet and Chase Farm NHS Trust (north-central sector)
- Guy's and St Thomas's NHS Trust (south-east sector)
- Mayday Healthcare NHS Trust (south-west sector)
- St. George's NHS Trust (south-west sector).

For each specialty where waiting times in OTs were relatively long (the 'choice' specialties), 'buddy' arrangements were developed with two RTs to which they could export patients awaiting designated surgical procedures. The buddy relationships between OTs and RTs are detailed in Figure 1 below:

Figure 1: Relationships between OTs and RTs

Barking, Havering and Redbridge

ENT	→	Central Middlesex Ambulatory Care and Diagnostic Centre (ACAD)*; HCA Princess Grace+
General surgery	→	ACAD*; University College London Hospital (UCLH)*
Opthalmology	→	Moorfields St. Ann's*; Western Eye Hospital
Orthopaedics	→	Royal National Orthopaedic Hospital (RNOH)*; UCLH*;
Urology	→	King's College Hospital; UCLH*

Barnet and Chase Farm

ENT	→	ACAD*; HCA Princess Grace+
General surgery	→	ACAD*; UCLH*
Gynaecology	→	King's College Hospital; Queen Mary's Sidcup
Opthalmology	→	Moorfields St. Ann's*; Western Eye Hospital
Orthopaedics	→	RNOH*; UCLH*
Urology	→	Chelsea and Westminster; UCLH*

Guy's and St. Thomas's

ENT	→	ACAD*; HCA Lister+
General surgery	→	King's College Hospital; Lewisham Hospital
Gynaecology	→	King's College Hospital; Queen Mary's Sidcup
Ophthalmology	→	Moorfields St. Ann's*; Western Eye Hospital
Orthopaedics	→	King's College Hospital; Ravenscourt Park Hospital*
Plastic surgery	→	London Bridge Hospital+
Urology	→	Chelsea and Westminster; King's College Hospital

Mayday Healthcare

ENT	→	ACAD*; HCA Lister+
General surgery	→	ACAD*; King's College Hospital
Gynaecology	→	King's College Hospital; Queen Mary's Sidcup
Orthopaedics	→	King's College Hospital; Ravenscourt Park Hospital*
Urology	→	Chelsea and Westminster; King's College Hospital

St. George's

ENT	→	ACAD*; HCA Lister+
General surgery	→	ACAD*; King's College Hospital
Orthopaedics	→	King's College Hospital; Ravenscourt Park Hospital*
Plastic surgery	→	Private hospitals
Urology	→	Chelsea and Westminster; King's College Hospital

* NHS treatment centre + private hospital

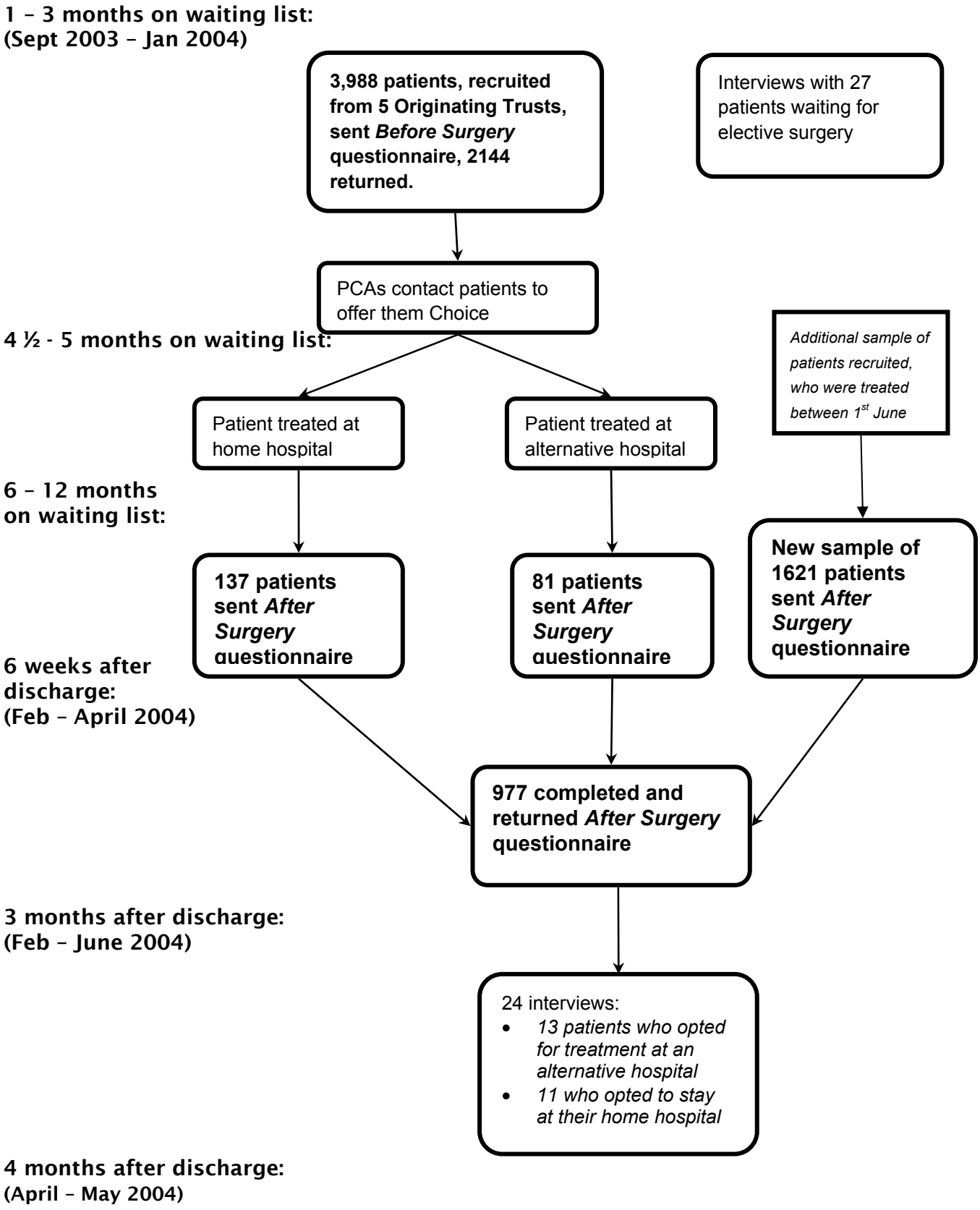
The *Before Surgery* questionnaire was sent to patients who had been on a waiting list at one of the five OTs for between one and three months. All patients who had spent at least one month on the waiting list for specified procedures in ENT, general surgery, gynaecology, ophthalmology, orthopaedics, plastic surgery and urology were included. Since all these patients were from hospitals where the usual wait for these procedures was more than nine months, it was assumed at the outset that the majority would be offered a choice of hospital. The questionnaire, which was mailed to patients before any choices had been offered to them, asked about their attitudes towards choosing a hospital and the factors that would influence their decision if they were offered a choice.

The *After Surgery* questionnaire, which asked about experience of hospital care and the choice process, was sent to patients who had initially been on a relevant waiting list at one of the five participating OTs. Recipients could have received treatment either at their originating OT or at one of the designated RTs. The questionnaire was mailed about six weeks after hospital discharge. Precise date of discharge was known to the study team for patients who had been treated at RTs, but had to be estimated for those treated at their home hospital.

The postal surveys were carried out using the Picker Institute's standard procedure, i.e. an initial mailing with a covering letter explaining the purpose of the study and a pre-addressed freepost return envelope, followed by up to two reminders to non-respondents at two-week intervals. A freephone number was made available to assist with any queries about the study and translation services were provided for non-English speakers via Language Line.

Figure 2 outlines the design of the study, the timings of the interviews and surveys and the numbers of patients involved at each stage.

Figure 2: Study design and patient numbers



3 Study sample

3.1 Response rates

A total of 2,144 patients returned completed *Before Surgery* questionnaires out of 3,988 originally mailed, a response rate of 54%. The response rate to the *After Surgery* questionnaire was 53% (977 out of 1,839). There was some variation between the trusts, ranging from 48% to 58% for the *Before Surgery* survey and 40% to 63% for the *After Surgery* survey (Table 2).

Table 2: Response rates to the *Before Surgery* and *After Surgery* surveys

Trust	Date joined study	Before Choice Survey			After Surgery Survey		
		Number of questionnaires sent to eligible patients	Responses received	Response rate (%)	Number of questionnaires sent to eligible patients	Responses received	Response rate (%)
Trust I	14th Oct 2003	1179	684	58.0	950	518	54.5
Trust II	18th Sept 2003	1192	609	51.1	528	284	53.8
Trust III	17th Dec 2003	546	262	48.0	91	57	62.6
Trust IV	13th Nov 2003	802	443	55.2	137	65	47.4
Trust V	4th Dec 2003	269	141	52.4	133	53	39.8
Total		**3988**	**2144***	**53.8**	**1839**	**977**	**53.1**

** Originating trust unknown for five respondents who removed the identifying code from their questionnaires*

While this response rate was comparable to that obtained from London patients in the national patient surveys, it was nevertheless lower than originally anticipated. When analysing survey data of this type it is important to be aware of any systematic biases in

the achieved sample, so data from the record review were used to compare responders and non-responders to explore possible reasons for non-response.

The record review revealed that a surprisingly small proportion of patients in Group A had been offered a choice of hospital (see Section 5 below for discussion on likely reasons for this). Non-responders in Group A were significantly less likely to have been offered a choice (26%, compared to 32% of responders). In cases where these patients (i.e. the non-responders) had been offered a choice, they were more likely to have opted to stay at their home hospital than those who responded to the survey (43% compared to 33%).

In Group B there was a contrast in response rates between those patients who had opted to remain at their home hospital and those who opted to receive treatment at an alternative hospital (Table 3).

Table 3: Response rates to *After Surgery* survey by hospital chosen (Group B)

Trust	**Treated at alternative hospital**			**Treated at home hospital**		
	Number of questionnaires sent to eligible patients	Responses received	Response rate (%)	Number of questionnaires sent to eligible patients	Responses received	Response rate (%)
Trust I	614	396	64.5	284	93	32.7
Trust II	273	168	61.5	141	38	27.0
Trust III	58	37	63.8	27	16	59.3
Trust IV	42	21	50.0	57	22	38.6
Trust V	57	35	61.4	68	14	20.6
Total	**1041**	**657**	**63.1**	**580**	**183**	**31.6**

Response rates were noticeably higher among those patients who chose to go to alternative hospitals (63% compared to 32%).

Patients in Group C (the cohort who had been sent both questionnaires) were significantly more likely to have returned the *After Surgery* questionnaire than those in Group B (i.e. those who had not been sent the *Before Surgery* questionnaire): 63%, compared to 53% among those in Group B (Table 4).

Table 4: Response rates to *After Surgery* survey by OT (Group C)

Trust	Number of questionnaires sent to eligible patients	Responses received	Response rate (%)
Trust I	52	29	55.8
Trust II	114	78	68.4
Trust III	6	4	66.7
Trust IV	38	22	57.9
Trust V	8	4	50.0
Total	**218**	**137**	**62.8**

It is clear that participation in the study was related to the extent of participation in the LPC scheme. Not surprisingly, patients not offered a choice were less likely to feel that the survey was relevant to their situation, so they were less likely to complete it. And those who were uninterested in the possibility of going to an alternative hospital were also less likely to complete the questionnaire. Patients in these two groups were therefore under-represented among survey respondents.

3.2 Characteristics of survey respondents

The two questionnaires included slightly different sets of socio-demographic questions. Information on age, sex, occupational status, procedure awaited/received, name of home hospital and self-assessed health status was collected for study Groups A, B and C, but in addition, the following data were obtained from Groups A and C who completed the *Before Surgery* questionnaire:

- Health status (EQ-5D)
- Age at completion of full-time education
- Household size
- Annual household income
- Ethnic group
- Caring responsibilities (for dependent child or sick, disabled or older person)

The following information was obtained only from Groups B and C who completed the *After Surgery* questionnaire:

- Social class (NS-SEC 2001)

Group C results have been subsumed within those for Groups A and B in the results that follow, unless otherwise stated.

3.3 Age, sex and ethnic background

Group A was fairly evenly balanced between men (52%) and women (49%). The age-distribution was similar for both sexes and half were aged over 60 (Table 5). Group B was similar (49% men and 51% women), but it included a slightly higher proportion of respondents aged 60 and over (60%).

Table 5: Sex and age of survey respondents

	Group A (*Before Surgery*)			**Group B (*After Surgery*)**		
Age-group	**Men (n=1,090) %**	**Women (n=1,030) %**	**Total (n=2,120) %**	**Men (n=474) %**	**Women (n=488) %**	**Total (n=962) %**
16-29	6.9	9.1	8.0	4.0	4.7	4.4
30-44	17.5	17.7	17.6	15.6	11.7	13.6
45-59	25.8	24.4	25.1	27.2	19.9	23.5
60-79	40.8	41.2	41.0	45.1	47.7	46.5
80+	9.0	7.7	8.3	8.0	16.0	12.1

Most Group A respondents were from white ethnic groups (85%), with smaller proportions reporting Asian (7%), Afro-Caribbean (6%), or mixed (1%) ethnic origin.

3.4 Education, income, employment and social class

Nearly two-thirds of Group A (62%) had completed their full-time formal education at the statutory school leaving age (16 or below), with the remainder having finished at 17-18 (16%) or post-19 (20%). Just over two per cent of respondents were still in formal education when they entered the study.

Just over a third (35%) of Group B were still in paid employment, compared to 39% of group A (Table 6). Reflecting the age distribution of the two samples, more than a third of Group A (38%) and nearly half of Group B (48%) had retired from paid work. In both samples, significantly more men than women were in paid employment and more women than men were looking after their home or family.

Table 6: Employment status of survey respondents

	Group A (*Before Surgery*)			Group B (*After Surgery*)		
Employment status	**Men (n=1060) %**	**Women (n=991) %**	**Total (n=2051) %**	**Men (n=473) %**	**Women (n=481) %**	**Total (n=954) %**
In paid work	43.8	33.9	39.0	44.6	24.9	34.7
Unemployed	4.9	3.2	4.1	2.3	2.9	2.6
Retired from paid work	37.6	38.4	38.0	42.7	53.6	48.2
Unable to work due to illness or disability	8.9	8.9	8.9	7.4	5.0	6.2
Looking after home or family	0.9	10.3	5.5	0.6	10.8	5.8
In full-time education	1.6	2.0	1.8	1.5	1.5	1.5
Other	2.3	3.5	2.7	0.8	1.2	1.0

Table 7 shows the breakdown by annual household income. More than half the respondents (53%) reported household incomes below the national average of £20,000 - £30,000. However, this question achieved a relatively low completion rate, with 22% of respondents unable or unwilling to provide information about their household income.

Table 7: Annual household income of survey respondents (Group A)

Annual household income	**Total (n=2144) %**
Less than £5,000	13.7
£5,000-£9,999	19.4
£10,000-£14,999	11.7
£15,000-£19,999	8.2
£20,000-£29,999	11.9
£30,000-£39,999	6.1
£40,000 and over	7.2
No answer/don't know	21.8

Social class was measured using the Office of National Statistics Socio-economic Classification (NS-SEC 2001, Table 8). Just over a third (37%) of men and nearly two-thirds (65%) of women were in managerial/professional or intermediate occupations. However, this section of the questionnaire was completed correctly by only 59% of respondents: less than half of the 461 respondents who had retired from paid work completed the relevant question set (49%).

Table 8: Socio-economic group of survey respondents (Group B)

Socio-economic group	**Frequency (n=580)** **%**
1 Managerial and professional occupations	33.1
2 Intermediate occupations	16.4
3 Small employers and own account workers	11.6
4 Lower supervisory and technical occupations	16.7
5 Semi-routine and routine occupations	22.2

Three quarters (75%) of those in Group A lived with at least one other person, while the remainder (25%) lived alone; 31% had caring responsibilities for children under 18 or for elderly or disabled adults.

3.5 Self-assessed health status

When asked to rate their health during the four weeks prior to completing the *Before Surgery* questionnaire, just under half of Group A (42%) said it was fair, poor or very poor. In contrast, less than a quarter (22%) of those in Group B reported health problems, reflecting the benefits of their recent treatment. In Table 9, these distributions have been compared to self-reported health status reported in the national NHS patient surveys carried out in 2002 and 2003 in each acute trust in England. The distribution of responses from Group A was broadly similar to that reported by national survey respondents recently discharged from inpatient care, while the distribution of responses among Group B closely resembled that of respondents to the national outpatient survey.

Table 9: Self-rated health status of survey respondents (Groups A and B)

Health status	Group A (n=2,109) %	National inpatient survey, 2002 (n=95,280) %	Group B (n=962) %	National outpatient survey, 2003 (n=90,552) %
Excellent	8.9	8.2	16.9	16.9
Very good	19.1	18.0	30.1	33.2
Good	30.3	26.4	31.0	28.6
Fair	27.0	32.4	17.3	15.1
Poor	12.4	11.8	4.0	5.0
Very poor	2.4	3.2	0.7	1.2

As was to be expected in a group of patients awaiting surgery, respondents reported a significant level of problems in relation to mobility, self-care, activities of daily living, pain and emotional state as measured by the EuroQol (EQ-5D) instrument (Table 10). A high proportion of those in Group A (80%) were experiencing pain, in many cases leading to restricted mobility and interference with their daily activities. Among Group C this percentage was even higher, with 88% reporting mild or moderate pain while awaiting treatment. Emotional problems (anxiety or depression) were reported by more than a third of respondents.

Table 10: Symptoms experienced while waiting for surgery

	% reporting any problem on EQ-5D	
Symptoms	**Group A (n=2,096)**	**Group C (n=133)**
Mobility	48.9	47.7
Self-care	14.2	13.5
Usual activities	49.2	51.5
Pain/discomfort	80.2	87.9
Anxiety/depression	36.0	33.8

3.6 Surgical procedures awaited/undergone

Nearly half of those in Group A (49%) were waiting for orthopaedic procedures and more than a quarter (26%) were awaiting operations in general surgery. Hip, knee and hernia operations predominated, but there was also a broad spread of other procedures (Table 11).

Table 11: Procedures awaited/undergone (Groups A and B)

	Group A			Group B		
Procedure	**Under 60 (n=1074) %**	**Over 60 (n=1047) %**	**Total (n=2121) %**	**Under 60 (n=399) %**	**Over 60 (n=564) %**	**Total (n=963) %**
Knee operation	25.9	32.7	29.2	30.1	32.8	31.7
Hernia repair	14.8	16.6	15.7	16.3	12.6	14.1
Hip replacement	5.0	16.7	10.8	4.8	16.1	11.4
Urological procedure	8.3	12.6	10.4	3.8	3.5	3.6
Ear/nasal surgery	14.6	3.1	8.9	7.3	0.7	3.4
Cholecystectomy	10.0	5.1	7.5	12.3	4.4	7.7
Varicose veins	7.3	3.4	5.4	12.0	2.8	6.6
Cataract or other eye operation	1.0	8.2	4.6	2.3	25.5	15.9
Tonsillectomy	6.5	0	3.3	6.3	0	2.6
Haemorrhoids	3.4	1.3	2.4	4.5	1.1	2.5
Hysterectomy and other gynae	2.9	0.2	1.6	0.3	0.4	0.3
Plastic surgery	0.3	0.1	0.2	0.3	0	0.1

The distribution of procedures undergone by Group B was broadly similar, except that it included a much higher proportion of cataract operations. This reflects the fact that Group B respondents entered the scheme at an earlier stage than those in Group A, at a time when cataract surgery predominated.

The distribution of operations was broadly similar between the age-groups except that hip replacements and cataract surgery were more common amongst the older group (over 60), whereas ENT operations, cholecystectomy and varicose vein operations were more prevalent among those aged under 60.

4 Views on choosing where to be treated[14]

The study design enabled us to look at the amenability of patients to choosing a hospital in four different ways:

- Asking **patients on hospital waiting lists** (Group A) if they would consider choosing an alternative to their 'home' (current) hospital for their operation. The *Before Surgery* survey elicited information about attitudes to the hypothetical concept of hospital choice before patients had actually been offered a choice.
- Undertaking a **record review of outcomes** to determine the proportion of patients in Group A who had opted for alternative hospitals and, in conjunction with their responses to the *Before Surgery* survey, comparing uptake among different social groups and examining factors that might have influenced their choices.
- Asking patients **after they had received their treatment** (Group B) which option they chose and why. The *After Surgery* survey looked at patients' experiences of making a choice and the outcome of their decision.
- Comparing attitudes to hospital choice **before and after surgery** (Group C), contrasting patients' attitudes while on the waiting list with their decisions and experiences after having been offered a choice.

4.1 Response to hypothetical questions about hospital choice

The majority of patients responded positively to the possibility of receiving their treatment at an alternative to their home hospital. In response to the question "If you were given a choice of having your operation at a hospital other than your home hospital, would you consider it", 40% said "Yes, definitely", and 42% said "Yes, possibly" , while only 18% said "No, not under any circumstances."

A generally high level of willingness to consider alternative hospitals was echoed in the interviews, with most interviewees responding positively to the idea that they could have a choice. Some indicated that this was a welcome departure from the usual experience in the NHS, while others saw it as their right. The offer of choice, even if not taken up, was viewed as being a good thing *per se* by a number of the interviewees:

> *"I think it's a nice option if you could choose. Obviously you go to whatever's nearest or wherever you get sent usually. It's a bonus to have an option, have a choice." (Interview A1: female, aged 67, waiting for hip replacement)*
>
> *"Patient choice is a right!" (Interview A26: female, aged 55, waiting for varicose vein operation)*

14 The names of hospitals have been anonymised in the results that follow.

"I just think choices are good. To be offered a choice is better than not being offered a choice. You don't have to take it do you!" (Interview A21: female, aged 49, waiting for varicose vein operation)

However, some interviewees felt that giving patients choice would lead to problems. Not everyone would be able to go to 'the best' hospital, so it could cause disappointment and resentment. While some of those who were less enthusiastic about the idea saw an analogy with popular schools being swamped with disappointed customers, others felt that quality of care might deteriorate in unpopular hospitals as patients drifted away:

"It's a stupid idea. It just confuses the issue doesn't it? I don't think you can really have hospitals doing all things to all people at your convenience. It just doesn't kind of work like that really. That's the same with the schools. [The] school there you can see, that's the reason I live here - it has a tremendous reputation but you see a lot of people want to go to that school but they can't get in". (Interview A17: male, aged 85, waiting for knee replacement)

"If the hospital or school or whatever has got a good reputation, everyone wants to have their surgery there or send little Willy to be educated there. The result is that you get hospitals that to a degree become blacklisted and isolated because other hospitals are more popular. So yes, it's a good idea but probably not a very practical one". (Interview A25: male aged 63, waiting for hernia repair)

While the majority of survey respondents in Group A were positive about hospital choice, there were some significant differences between sub-groups. Table 12 shows the proportion responding positively to the question about willingness to go elsewhere (those who said they would "definitely" or "possibly" go to an alternative hospital) among different social groups.

Table 12: Willingness to consider an alternative hospital by socio-economic status (Group A)

		% "definitely" or "possibly" willing to consider alternative hospital	
Sex:	female (n=1008)	80.5	
	male (n=1073)	83.1	n.s.
Age-group:	over 60 (n=1018)	75.6	
	under 60 (n=1060)	87.8	p<0.001
Educational status:	basic[15] (n=1257)	79.4	
	higher (n=777)	87.0	p<0.001
Employment status:	not employed (n=1232)	77.4	
	employed (n=793)	89.8	p<0.001
Household income:	below average[16] (n=1117)	79.4	
	above average (n=533)	93.4	p<0.001
Health status:	poor[17] (n=863)	78.9	
	good (n=1203)	84.3	p<0.001
Ethnic group:	non-white (n=281)	80.1	
	white (n=1681)	82.4	n.s.
Household size:	single (n=513)	79.9	
	two or more (n=1526)	83.1	n.s. .
Caring for dependents:	no (n=1402)	81.8	
	yes (n=611)	84.0	n.s.

15 Completed education at statutory school leaving age

16 Below £20,000 per annum

17 "Fair", "poor" or "very poor" on six-point scale

Younger people were more willing than older people to consider going to an alternative hospital (88% of those aged under 60 as compared to 76% of those over 60). Significant differences were also observed in relation to education status (87% of those with higher education as against 79% among those without), employment status (90% of those in paid employment against 77% of those not employed), household income (93% with above average incomes compared to 79% of those below) and health status (84% of those rating their health as good or better, compared to 79% of those who rated it fair or worse).

In most cases the more advantaged groups were more likely to express willingness to consider an alternative hospital. After adjusting for sex, age and health status, those in the more advantaged groups (higher educated OR 1.37 (95% CI 1.05-1.78), $p<0.05$), currently employed OR 1.93 (1.40-2.67), $p<0.001$), and those with higher household incomes OR 2.68 (1.80-3.99), $p<0.001$) were significantly more likely to be willing to consider going to an alternative hospital.

4.2 Factors influencing response to hypothetical choices

Respondents to the *Before Surgery* survey who said they would be willing to consider going to an alternative hospital were asked to rate the importance of various factors that might influence their choice. These factors were ranked by assigning a score of 2 if the respondent ticked “very important”, 1 if they ticked “quite important” and 0 if they ticked “not at all important”. Table 13 shows the proportion of respondents indicating that this was a “very important” factor, together with the average scores for each factor.

Greater importance was accorded to good clinical outcomes, a clean environment, reputation of surgeon and hospital, and continuity of care than to shorter waiting times, possibly because respondents felt that a shorter wait would be guaranteed if they chose an alternative provider. Practical considerations were also important to the survey respondents, but the type of hospital was ranked considerably lower than the other factors.

Table 13: Factors that would influence choice of hospital (Group A)

Factor	N	Mean	% saying "Very important"
High success rates for operation	1666	1.855	86.7
High standard of cleanliness	1663	1.853	86.1
Good communication between hospitals and GP	1659	1.808	82.6
Reputation of surgeon	1649	1.745	77.1
Follow-up care close to home	1670	1.717	74.1
Reputation of hospital	1644	1.689	72.1
Shorter waiting time	1655	1.610	64.5
UK not abroad	1631	1.207	46.2
Friends and family can easily visit	1626	1.105	37.5
Comfortable journey	1636	1.160	36.9
Not too far from home	1659	1.151	36.8
Free transport	1640	1.014	34.0
Free accommodation for companion	1594	0.756	25.2
NHS hospital	1600	0.661	18.5
Teaching hospital	1516	0.567	15.9
Private hospital	1571	0.544	14.8

There were marked differences between the age-groups in the importance attributed to some of the factors. For example, older people (over 60) were more likely to say that cleanliness was very important (89% compared to 84% among the under 60s, $p<0.005$), more likely to stress the importance of a comfortable journey between home and hospital (43% compared to 32%, $p<0.001$), more likely to stress the importance of accessibility to visitors (41% compared to 35%, $p<0.001$), and more likely to want to go to an NHS hospital (26% compared to 13%, $p<0.001$).

4.3 Waiting times

Naturally, patients on the waiting list hoped that treatment would reduce or eliminate the symptoms for which they had originally sought help. Waiting for surgery can be a distressing experience, with many patients continuing to suffer painful symptoms,

physical limitations and disruption to their daily activities (see Table 10, p.21). Interviewees provided graphic descriptions of how it felt to suffer the symptoms while waiting for surgery. Some feared their condition would deteriorate if they didn't have surgery soon and for some the symptoms had prevented them from working or forced them into early retirement. Most wanted to have their operation as quickly as possible, to get relief from pain and discomfort, and to get on with life:

> *"I would very, very quickly agree to it because nobody wants to live with pain. The older you are the less you want to live with pain, and I can put up with quite a bit. But at times I feel "What am I here for, putting up with all this?" I think it's nicer if you can look forward to having it done in a reasonable time, not this dragging on with nothing happening". (Interview A7: female aged 83, waiting for knee arthroscopy)*

Some said that while they could cope at the moment, their attitude to choosing an alternative hospital would depend on their health state at the time the offer became available. If their condition had worsened, they would be much more likely to take up the offer of faster treatment elsewhere:

> *"That would depend on what sort of condition I was in. When I had my first knee done, I was in excruciating pain and I might have said yes to anything at that time just to get it over with, to get relief from the suffering. So far this knee is very painful but it isn't as bad, so I think you have to judge it on those sort of things". (Interview A4: female aged 62, left knee replacement)*

Group A survey respondents were asked how long they had been on the waiting list for the relevant surgical procedure. Despite the fact that patients had been recruited to the study when they had officially been waiting for between one and three months, many reported longer waits: 14% said they had waited longer than six months and 4% said they had waited 12 months or more. Some respondents may have been confused about the date their name was first placed on the waiting list for surgery. Not unreasonably, many patients assessed their waiting time as having started at the point when their GP first referred them to a hospital specialist. It is also possible that some had indeed been on the official waiting list for longer than three months, but this had not been accurately reflected in the hospital records or had been reset due to a cancelled appointment.

Respondents were asked if anyone had told them how long they would be likely to have to wait for their operation. Nearly two-thirds (65%) said they had been given an estimate of their likely waiting time by hospital staff, while others had been told by their GP (5%) or by someone else (3%). Only 18% of respondents had been given an actual admission date for their operation. Of these, 23% said the date had been changed by the hospital at least once, 13 patients said it had been changed two or three times and two patients said it had been changed four times.

Several of the interviewees were confused about exactly when the clock starts to tick in relation to waiting for surgery, and some suspected that 'hidden' unofficial waiting lists were in operation, in addition to the officially published ones.

> *"It's a bit difficult because they give you the thing saying that they can't do it before a certain time, but it's difficult to get really what the problem is about having the operation, or at least putting you on the waiting list. They've said they've put me*

provisionally on it, but I don't know whether that means you're actually on the waiting list or whether they're waiting for a certain thing and then you're going to go onto the main list." (Interview A5: male aged 54 waiting for knee operation)

"They're very clever in [Trust IV] because they actually write to you and say that your GP has contacted them, they know that you need treatment and they will write to you when you are going onto the waiting list. I had to wait then 18 months before they sent me a letter to say I was going on the waiting list and that's how they're keeping the figures down on paper, because they're acknowledging the fact that you are waiting for treatment, but they're not putting you on the waiting list." (Interview A12: female aged 50, waiting for varicose veins operation)

A general scepticism about the effects of the drive to meet waiting time targets influenced some interviewees' views of the LPC scheme. Some saw it as a cynical attempt to improve government statistics, rather than a genuine attempt to improve patients' experience.

"I'm not saying you shouldn't have the choice, but I sometimes wonder if it's a case of just reorganising the figures so that the figures look better for one hospital than they do another. There could be that element of "Oh well, we're not that busy, this hospital's very busy, so we'll take some of their patients which equals the busyness out.'" (Interview A23: female aged 51, waiting for varicose veins operation)

There were significant differences in expected waiting times between the OTs, as well as variation in whether or not information about likely waiting time was provided (Table 14). In particular, patients at Trust IV were much more likely to report that they had been given an estimated length of wait, whereas nearly half (44%) of those on the waiting list at Trust V said they had not been told how long they might have to wait for their operation. In total 11% of Group A respondents expected to have to wait more than a year and a further 20% expected to wait 9-12 months.

Table 14: Expected waiting time by OT (Group A)

Length of wait	**Trust I (n=640) %**	**Trust II (n=574) %**	**Trust III (n=240) %**	**Trust IV (n=425) %**	**Trust V (n=131) %**	**Total (n=2010) %**
Less than 3 months	4.7	5.9	11.3	7.1	10.7	**6.7**
3 - 6 months	7.8	16.4	17.1	12.7	19.1	**13.1**
6 – 9 months	22.3	21.4	16.7	21.9	12.2	**20.6**
9 – 12 months	27.3	12.7	9.6	28.5	9.2	**20.1**
12 months or more	9.2	12.5	6.3	14.6	5.3	**10.7**
No information about likely wait	28.6	31.0	39.2	15.3	43.5	**28.7**

Nearly two thirds (65%) of Group A survey respondents placed great value on a shorter waiting time. However, there was no relationship between willingness to consider going to an alternative hospital and the length of time patients expected to have to wait at their home hospital. Those who had been led to believe that they would experience a relatively short wait of less than three months were just as likely to be willing to consider an alternative hospital as those who expected a longer wait.

In discussing the LPC scheme, the advantage of a reduced waiting time was immediately apparent to most interviewees, even if it meant going into hospital at short notice. Long waits were felt to exacerbate the anxiety of anticipating surgery. For others, the benefits of the choice scheme lay in the fact that they would have a clear indication of exactly when they would have their operation, in contrast to their present state of uncertainty about the admission date:

> *"It's good to have a choice, to have it done more quickly than dragging and hanging on worrying yourself until the time comes. If you're not absolutely sure what's wrong and you need to have a scan and all that, you start worrying and panicking. I think it's good for them to have a choice yes." (Interview A13: female aged 44, waiting for haemorrhoidectomy)*

> *"Choice I think is excellent if you could get some idea how long it's going to be. It's the "not knowing" how long it's going to take... (Interview A18: female aged 73, waiting for hip replacement)*

4.4 Facilities and quality of care

When considering their likely reactions to the offer of an alternative hospital, survey respondents placed standards of hospital cleanliness very high in their list of priorities, with 86% saying it would be a very important factor in deciding where to be treated. Concerns about cleanliness did not arise simply because of aesthetic sensibilities; poor standards of hygiene were felt to increase the risk of contracting infections. Some interviewees gave graphic descriptions of previous experience of infection in hospital and its devastating effects:

> *"Because of a urine infection I spent another two weeks in hospital when I should have just gone in for a week, had it done, come home and I'm alright. That made me very angry because I should not have got that kind of infection and what it's caused through is just cleanliness, that kind of thing". (Interview A13: female aged 44, waiting for haemorrhoidectomy)*

> *"Good treatment would be high on my list, cleanliness. My father died recently in hospital and not from the illness that he had, but because he caught this bug from the hospital. He ended up dying of internal bleeding because they hadn't picked it up soon enough. (Interview A12: female aged 50, waiting for varicose veins operation)*

Coordination between clinical staff was also seen as an important factor. When considering the possibility of going to a different hospital, respondents were concerned that all professionals involved in their care should know what was happening to them,

including their GP. Some interviewees said they were willing to consider having their operation at a distant hospital, but would prefer to have their after-care at their local hospital. Others were worried about communication problems between staff if they had to undergo treatment at two different hospitals, fearing their records might get lost. Ultimately, it was felt to be important that some form of follow-up care was provided, and that both the patients and all staff involved in their care were aware of whose responsibility it was to provide this, and where it would take place.

Patients' willingness to consign themselves to the care of a particular hospital was influenced by their perception of its reputation. The questionnaire asked respondents to rate the reputation of their home hospital. The results are shown in Table 15. It is apparent that Trust III inspired more loyalty among its patients (90% rated its reputation as good or better) than the other OTs. This is perhaps not surprising. Trust III is a world-famous inner-city teaching hospital and tertiary referral centre which also provides services for local communities in a relatively deprived part of London. It achieved three stars in the 2002/3 and 2003/4 performance ratings and is now a foundation trust. Trust II, which received the lowest rating (only 53% rated its reputation as good or better), serves a population of half a million people living in outer London. It was awarded only one star in 2002/3 and none at all in 2003/4, so the relatively poor rating it received from survey respondents may reflect local concern about the trust's performance. The other three trusts each received two stars in the 2002/3 and 2003/4 performance ratings apart from Trust I whose rating was reduced to one star in 2003/4. Trust V, the other major teaching hospital and tertiary centre in the group, serving a mixed inner-city and suburban population, was not quite as popular as Trust III, although 78% gave it a positive rating for reputation. Trust I, which operates across four main sites and is one of the largest acute trusts in England, and Trust IV, with two sites, are district general hospitals serving diverse populations. Around two-thirds of their patients (67% in Trust I and 63% in Trust III) said their reputations were good or better.

Table 15: Perceived reputation of each of the OTs (Group A)

	Trust I (n=662) %	**Trust II (n=594) %**	**Trust III (n=249) %**	**Trust IV (n=433) %**	**Trust V (n=135) %**	**Total (n=2073) %**
Excellent	8.3	4.7	26.1	5.1	5.9	**8.6**
Very good	21.9	17.3	36.1	22.4	32.6	**23.1**
Good	36.3	31.3	28.1	35.6	39.3	**33.9**
Fair	22.8	25.6	7.2	24.2	17.0	**21.7**
Poor	6.8	14.6	1.6	9.0	4.4	**8.7**
Very poor	3.9	6.4	0.8	3.7	0.7	**4.0**

Willingness to consider going to an alternative hospital varied according to the OT at which patients were currently waiting (Table 16). In all but one of the OTs, more than 80% of patients were willing to consider having their operation at an alternative hospital. The exception was Trust III, where nearly a third of patients (29%) were unwilling to consider going elsewhere.

Table 16: Willing to consider alternative hospital by OT (Group A)

	Trust I (n=669) %	Trust II (n=596) %	Trust III (n=253) %	Trust IV (n=438) %	Trust V (n=138) %
Yes, definitely	45.3	37.2	28.9	44.1	37.0
Yes, possibly	38.6	44.0	39.9	41.3	48.6
No, not under any circumstances	16.1	18.8	31.2	14.6	14.5

The relationship between views on a hospital's reputation and willingness to receive treatment elsewhere is shown in Table 17. There was a very clear trend: those who felt their home hospital had an excellent reputation were much less willing to consider being treated elsewhere than those who felt their home hospital's reputation was poor.

Table 17: Willingness to be treated elsewhere by views on OT's reputation

	Yes, definitely (n=822) %	Yes, possibly (n=845) %	No, not under any circumstances (n=378) %
Excellent	31.2	33.5	35.3
Very good	31.5	41.7	26.8
Good	37.2	44.1	18.7
Fair	47.7	42.3	10.1
Poor	53,1	39.7	7.3
Very poor	65.9	30.5	3.7

It was apparent that patients distinguished between hospitals on the basis of their perceived reputation, but the issue is quite complex. When interviewees were asked to rate the reputation of their home hospital, they tended to refer in the strictest sense to general public opinion about that hospital, taking into consideration positive or negative accounts related by patients and visitors, media reports and so on. In other words: "How good is the hospital reputed to be?" However, when they were asked to talk about their interpretation of the concept of 'reputation', other meanings often came into play. While patients were happy to comment on what they had heard about the hospital from family, friends and media sources, they also drew on their own personal experience either to confirm or refute the public perceptions. Personal experience often overruled the public view, and can be considered an entirely distinct element of patients' views on their home hospital. The question was often reinterpreted as: "How good is the hospital for me?" If a patient's personal experience of a hospital was negative, this did not inevitably mean that they would choose not to return to that hospital for treatment, because other factors such as familiarity and convenience were viewed as equally, if not more, important. Considerable value was placed on knowing what to expect in terms of staff, surroundings and procedures. If the hospital was perceived as easy to get to, both for the patient and for any visitors they might have during their hospital stay, then concerns about its reputation or the general quality of care were often downplayed.

The reputation of the surgeon who would carry out the operation was also felt to be important. Patients' opinions about a surgeon's reputation were related to various factors including perceptions of his or her competence, qualifications, communication skills, safety record and clinical outcomes. In many cases reputation was equated with experience. Interviewees stressed the importance of having an experienced surgeon, saying they wouldn't want to be operated on by a junior doctor. The surgeon's reputation and experience was seen by many as more important than, but also closely connected to, that of the hospital:

> *"I really wouldn't want a trainee doctor to be operating on me. I know it does happen, otherwise they don't become doctors, but I personally wouldn't want it. The hospital itself or the reputation of the hospital, as far as I'm concerned, would be as good as the reputation of the doctor or the surgeon". (Interview A23: female aged 51, waiting for varicose veins operation)*

> *"The bloke in [Trust III] who runs the show (the consultant), should probably be retired, but there's nobody else who's got the knowledge that he's got. You don't want a nineteen year old first year surgeon larking about because he's learning." (Interview A8: male aged 72, waiting for hip replacement)*

But personal knowledge of a particular surgeon or word-of-mouth reports from other patients were the main sources of information for most people. Few interviewees had any idea how to find out if a surgeon was 'good'.

Most patients waiting for surgery believed it would provide relief from pain and discomfort. In choosing a hospital, therefore, they placed a high priority on achieving a successful outcome. However, patients felt ill-equipped to make comparisons between hospitals in respect of their success rates in performing specific surgical procedures. Some patients mentioned that they would want specific information about clinical outcomes before deciding where to go for treatment, but most of those expressing a

desire for information about these topics indicated that they had no idea how or where to find this information. On the other hand, many others expressed no interest in such information, assuming that treatment outcomes would be similar at all hospitals.

4.5 Practical considerations

Availability and cost of transport was an important consideration for many interviewees when thinking about whether they'd be willing to go to an alternative hospital:

> *"Provided it didn't cost me anything I'd go. Halfway round the world is Australia isn't it? I'd go there. I know there are people who won't move ten miles and they want to be close to their mother, or I'd like my relatives to visit me. I couldn't give a monkey's and neither could my relatives, they'd much prefer to see me being 'me' than miserable." (Interview A8: male aged 72, waiting for hip replacement)*

> *"I'd have to find out about the transport thing, because I don't drive and so I'd obviously have to know what the arrangements were, whether the hospital covers the transport. That's the main thing I think. They'd have to fetch me, I think, because with these knees I can't do stairs you see and I don't get on and off the buses easily or the train. I would prefer to be picked up from my residence and taken". (Interview A7: female aged 83, waiting for knee arthroscopy)*

Travel times across London depend on route and mode of travel, more than distance. Most Group A survey respondents (90%) said it usually took them less than an hour to get to their home hospital. More than half said they usually travelled by car, while just under a third went on public transport. These patterns varied between OTs, with 58% of patients at Trust III saying they usually travelled by public transport, compared to 39% at Trust V, 36% at Trust IV, 23% at Trust I and 22% at Trust II.

Some interviewees awaiting day case surgery were worried about travelling a long distance for treatment in case it might extend what was intended to be a brief spell in hospital. These patients saw various advantages of day case surgery, for example short time off work and the relative ease of arranging a lift, and were concerned that travelling further afield for treatment would involve greater inconvenience.

> *"My surgery is only going to be day surgery. To be sent somewhere else in England and then have perhaps a five hour journey home after that surgery they might say: well you might have to be an inpatient for a couple of days afterwards. I can walk to [Trust IV] from where I live. That would be quite important to me because I can be home in a car in five or ten minutes. (Interview A23: female aged 51, waiting for varicose veins operation)*

> *"With the day thing you take yourself in and you bring yourself back. I wouldn't want to go too far purely because I'm imposing on somebody to have to come and wait for me in that instance. When I'm at home I can ask somebody to drop me off on their way to work and I can say to someone else to pick me up on their way back from work, or I can say to my husband: come when you're finished work." (Interview A24: female aged 54, waiting for varicose veins operation)*

Prior experience of travelling to an alternative hospital tended to override concerns about distance. Interviewees who knew how to get to a hospital outside their area and wanted to go there again were less concerned about how far away it was. Others were concerned

about organising a lift or paying for a taxi and finding the way to an unfamiliar hospital. Unwillingness to travel relates more to concerns about the means of transport than to time or distance *per se*.

Many of those considering travelling to a more distant hospital had to think about the likely impact of their decision on their friends and family. The majority of Group A survey respondents (79%) expected a companion would accompany them to hospital when it was time for their operation and more than a third (38%) said that accessibility for their visitors was a very important consideration. Despite this, 80% said they would be willing to go into hospital for treatment at relatively short notice, i.e. with at least two weeks warning. But having enough notice to organise their affairs, including work and childcare, was also of major concern to some interviewees who wanted the certainty of a guaranteed date:

> *"You'd go for the shorter option, but the shorter option would have to work. I couldn't organise everything and then it not happen. It would have to be guaranteed. If the hospital were to phone me up tomorrow and say: I've got a cancellation for next week, can you take it? I would have to say yes, and then hope that when I came into work they could sort something out. (Interview A25: female aged 51, waiting for varicose veins operation)*

The abstract notion of having a choice of hospital was popular among study participants, but the decision about where to undergo surgical treatment raised a complex set of issues for them. Patients have to weigh up various factors, including the perceived urgency of treatment, the likely quality of care in different hospitals and the facilities they could offer, alongside practical considerations to do with transport, timing and convenience for themselves and their relatives. These practical concerns tended to weigh more heavily for those in less advantaged groups.

5 Who was offered a choice?

At the outset of the study all patients in Group A had been considered by waiting list administrators at their OT to be eligible for the LPC scheme, in that they were registered with a London GP, were waiting for a specified 'choice' procedure and were facing a probable wait of more than eight months. Despite this, the record review revealed that more than two-thirds of those in Group A (68%) were not in the end offered a choice of hospital.

There were several reasons why patients could be legitimately excluded from the offer of choice:

- Patient was not contactable
- Operation was cancelled, either by the patient or the hospital
- Patient was excluded because of specific co-morbidity
- Treatment became available at their OT within eight months of joining the waiting list.

The review of LPC records enabled us to identify all those patients whose names had been forwarded by OTs to the PCAs with a view to being offered a choice of hospital. The list included outcome codes for all those approached by the PCA team. These revealed that only 70 of the 2,139 patients in Group A (3%) were excluded after their names had been forwarded to the PCAs, either because they could not be contacted or because their operation was cancelled for some reason. The remaining patients did not appear on the list at all, presumably because their names had not been forwarded to the PCAs. These patients may have had their operation within the eight month time limit, or they already had a date for admission and were therefore excluded (18% of Group A respondents said they had been given an admission date), or they were excluded for clinical reasons, or they remained on the waiting list at their home hospital but for some reason were not offered the opportunity of having faster treatment through the LPC scheme, or their names did not appear on the LPC database for some other reason. The final *Before Surgery* questionnaires were mailed in January 2004 to 1,400 patients placed on the waiting list at OTs in November or December. The final record review was carried out in July when these patients would have been on the waiting list for seven or eight months, so in theory their names should have appeared on the database.

At the point of recruitment of patients into the study (after one month on the waiting list) hospital administrators did not necessarily know with any certainty how long the patients were likely to have to wait for their operation. Nor did they know the outcome of the 'validation' procedure whereby patients were screened for eligibility for the LPC scheme, if this had not yet taken place. Two types of validation were undertaken before patients' names were passed on to the PCA team: waiting list validation, whereby patients were telephoned to confirm their contact details and to check whether they still required surgery; and clinical validation, in which they were screened for the presence or absence of clinical exclusion criteria (see Table 1). There were variations between OTs in the procedures adopted. For example, in some OTs patients were simply sent a standard letter in which they were asked if they were interested in participating in the LPC scheme. If they failed to respond, they were automatically excluded from the list sent forward to the PCAs. This 'opt-in' system effectively reduced the proportion of patients offered a

choice. There was no evidence from our data that OTs or PCAs operated any other discriminatory criteria. For example, variables such as age, sex, level of education, employment status, income, ethnic group, household size, or whether patient was caring for dependents, were not significantly related to whether or not patients were offered a choice. But it was apparent that staff in some trusts were confused about the procedure they were supposed to follow in recruiting patients into the scheme and this resulted in some inappropriate exclusions.

Clinical validation was supposed to take place before the patient had been on the waiting list for four months, and ideally before the PCA contacted patients to inform them about the choice process. This validation process was carried out with varying degrees of thoroughness at different OTs. In some trusts consultants checked the patients' notes, while in others validation was carried out by administrative staff without specialist clinical knowledge. It was possible, therefore, for patients to be excluded from the choice scheme at a later stage (i.e. after the point when the initial PCA contact occurred). In some cases patients attending pre-operative assessment clinics at RTs were deemed unfit to undergo their procedure in a treatment centre and were referred back to their OT. This could be very confusing for patients and required sensitive handling

There was significant variation between the OTs in the proportion of patients offered a choice of hospital (Table 18). Trusts known to have the longest waiting times (Trust I and Trust II) were more likely to submit patients for the LPC scheme, whereas Trust III and Trust V offered a choice to significantly fewer patients. Possible explanations for this include fewer patients facing a wait of more than 8 months, higher incidence of exclusion criteria, or lack of co-operation with the LPC scheme for administrative or other reasons.

Table 18: Proportion offered a choice by OT (Group A)

Originating Trust	**% offered choice**
Trust I (n=684)	33.0
Trust II (n=609)	41.9
Trust III (n=262)	21.4
Trust IV (n=443)	30.0
Trust V (n=141)	13.5
Total (n=2,139)	**32.2**

Patients awaiting procedures in certain specialties (notably ophthalmology, 49%) had a higher likelihood of being offered a choice of hospital (Table 19). The variation between the specialties was also apparent within individual Trusts. For example, no study patients from Trust III awaiting procedures in gynaecology, ophthalmology, plastic surgery or urology were offered a choice, possibly because waiting times in these specialties were relatively short.

Table 19: Proportion offered a choice by specialty (Group A)

Specialty	% offered choice
ENT (n=262)	35.5
General surgery (n=662)	29.6
Gynaecology (n=33)	9.1
Ophthalmology (n=101)	48.5
Orthopaedics (n=853)	33.8
Plastic surgery (n=4)	0
Urology (n=224)	26.8

In some cases it appeared that the possibility of losing their patients to an alternative hospital had encouraged OTs to reorganise their services so as to reduce waiting times, with the result that in some specialties no patients fell within the LPC criteria. In the event, no study patients awaiting plastic surgery procedures were offered a choice through the LPC scheme and the numbers were small in gynaecology (n=33). In other cases, OTs made specific local arrangements with private hospitals to treat patients who might otherwise have had a long wait. Technically speaking these arrangements fell outside the LPC scheme. These patients were usually offered only one alternative hospital, not two as was the recommended standard in LPC.

On the face of it, the fact that less than a third of those apparently eligible for the scheme were actually offered a choice of hospital is surprising, given the long waiting times prevalent in these London hospitals. The most likely explanations for this are:

- Inaccurate assessment at the outset of the scheme of numbers of patients facing waits of more than six months;
- The scheme, coupled with other waiting list initiatives occurring concurrently, had succeeded in galvanising OTs to speed up throughput in elective surgery, thus reducing waiting times;.
- A much higher than expected number of exclusions due to significant co-morbidities;
- Administrative problems resulting in a failure to identify eligible patients and forward their names to the PCAs within the specified time limit;
- OTs were not cooperating with the system, i.e. finding spurious reasons to hold on to their patients.

Data gathered in this study cannot shed light on which of these reasons is closest to the truth, but plausible explanations may emerge from other parts of the LPC evaluation.

6 Reactions to the offer of a choice of hospital

6.1 Uptake of alternative hospitals

The majority of Group B interviewees were extremely positive about having been offered a choice, including those who had chosen to remain at their home hospital. Symptom relief was for many the over-riding priority:

> *"Anything to get rid of that pain. The drugs were no longer working….when you're in pain like that and they say you can have it done tomorrow if you go somewhere, you'd go there no matter how far it was!" (Interview B9, male aged 63, had hip replacement at an alternative NHS trust)*

> *"The hip got really bad…I had to be careful how I turned and things like that. It was very painful, terribly painful, so I was glad - that hospital was so incredible – it was an amazing hospital!" (Interview B3, female aged 69, had hip replacement at NHS treatment centre)*

> *"I think it's a good scheme. They give choice to the patient. It's not that you are totally committed to like the home one. They give the choice and it's all up to the patient concerned what he thinks or what she thinks". (Interview B6: male aged 67, had prostate operation at Trust IV)*

Using data from the record review to look at outcomes of the decision process amongst respondents to the *Before Surgery* questionnaire we were able to estimate the rate of uptake of an alternative hospital. This showed that two thirds of Group A patients who were offered a choice (67%) chose to undergo treatment at an alternative to their home hospital, i.e. at an RT.

The record review was also used to check outcomes for those in the cohort group (Group C). Of these 218 patients, 137 (63%) were offered a choice and decided to go to an alternative hospital, 57 (26%) were offered a choice but decided to remain at their home hospital, 17 (8%) were not offered a choice, three were uncontactable, one patient had already had their operation, in two cases the operation was cancelled by the RT and in one case the operation was cancelled by the patient. The rate of uptake among this sub-group was similar to that in Group A, but the proportion actually offered a choice was much higher.

We were interested to see if the social group differences we had observed in response to the hypothetical notion of being offered a choice were reflected in actual uptake. Table 20 shows the comparisons between the different sub-groups in relation to decisions taken. Most of the differences observed previously were no longer apparent. People in paid employment were significantly more likely to opt for an alternative hospital than those not in paid employment OR 1.63 (1.05-2.53), $p<0.05$), but no educational or income differences were observed, neither were there any significant differences in rates of uptake by sex, age-group, health status, ethnic group, household size or carer status.

Table 20: Uptake of alternative hospital by socio-economic status (Group A)

		% opting for alternative hospital	
Sex:	female (n=300)	68.7	
	male (n=311)	64.6	n.s.
Age-group:	over 60 (n=317)	64.7	
	under 60 (n=294)	68.7	n.s.
Educational status:	basic (n=369)	65.2	
	higher (n=227)	67.2	n.s.
Employment status:	not employed (n=372)	63.4	
	employed (n=220)	72.7	p<0.05
Household income:	below average (n=321)	68.2	
	above average (n=151)	66.9	n.s.
Health status:	poor (n=249)	69.1	
	good (n=357)	65.5	n.s
Ethnic group:	non-white (n=89)	66.3	
	white (n=489)	67.3	n.s.
Household size:	single (n=151)	62.3	
	two or more (n=447)	67.8	n.s.
Caring for dependents:	no (n=412)	64.9	
	yes (n=174)	67.2	n.s.

Group A patients who had responded positively to the idea of choosing an alternative hospital in the *Before Surgery* survey were significantly more likely to opt for treatment with an alternative provider when they were actually offered a choice, but nearly a third of

those who had said they would not consider going elsewhere had changed their mind (Table 21).

Table 21: Willingness to consider alternative hospital by decision made (Group A)

	Chose home hospital (n=199) %	Chose alternative hospital (n=405) %
Would consider alternative hospital	27.3	72.7
Would not consider alternative hospital	68.7	31.3

Nearly three quarters (73%) of those who had said they would consider an alternative hospital actually did so, as against just under a third (31%) of those who initially said they would not consider going elsewhere but ultimately opted to go to an alternative hospital. The proportions were slightly higher among the cohort sample (Group C): 47% of those who had said they would not consider going to an alternative hospital eventually did decide to be treated elsewhere, as compared to 79% of those who had been willing to consider it in the first place. It is worth noting that Group C included only patients who had undergone surgery in 2004, whereas Group A had completed their treatment in 2003. This is suggestive of an upward trend in the rate of acceptance of the offer of an alternative hospital.

There were several reasons why patients may have changed their minds. In some cases the amount of pain they were experiencing may have increased or decreased, and for others the information provided by the PCA may have helped to allay their fears. For some patients the change of heart was due to the reassurance that practical arrangements, such as transport, would be provided free:

> *"I really didn't have a choice, I think that's basically it. I mean you get pretty desperate when you're in pain all the time." (Interview B6: female, aged 68, had hip replacement at NHS treatment centre)*

> *"When they said to me I could either go to two hospitals. What I was more worried about is how to get there? I don't like driving where I don't know, so it was quite nice to have someone take me where they know. Because that was my first question to them, when they said about picking me up, I said 'Is it going to cost me?'" (Interview B5: female aged 35, had cholecystectomy at NHS treatment centre)*

The proportion of patients opting to receive their treatment at an alternative to their home hospital varied by OT (Table 22). Trust I had the highest uptake (76%), followed by Trust II (74%), while significantly fewer patients from Trusts III, IV and V opted to have their operation at an alternative hospital.

Table 22: Uptake of alternative hospital by OT (Group A)

	% treated at an alternative hospital
Trust I (n=213)	75.6
Trust II (n=235)	73.6
Trust III (n=45)	40.0
Trust IV (n=107)	46.7
Trust V (n=17)	52.9
Total (n=617)	**66.6**

There was a clear indication that the level of pain patients experienced while on the waiting list affected their choice. Those who reported the greatest amount of pain prior to undergoing surgery were significantly more likely to accept the offer of an alternative hospital ($p<0.01$) (Table 23).

Table 23: Pain experienced by choice of hospital (Group A)

	Chose home hospital (n=203) %	Chose alternative hospital (n=399) %
No pain or discomfort	44.5	55.5
Moderate pain or discomfort	32.4	67.6
Extreme pain or discomfort	26.1	73.9

Patients waiting for procedures in some specialties were more likely to opt for an alternative provider than patients in other specialties. In particular general surgery patients tended to be more likely to opt for treatment at their home hospital ($p<0.05$) (Table 24). This may be because many were awaiting relatively minor procedures, such as hernia repair or varicose veins operations, often carried out on a day case basis and perhaps not perceived as especially urgent by patients.

Table 24: Choice of hospital by specialty (Group A)

Specialty	Chose home hospital (n=206) %	Chose alternative hospital (n=410) %
Ophthalmology	29.2	70.8
General surgery	41.8	58.2
Orthopaedics	31.9	68.1
ENT	23.5	76.5
Urology	34.0	66.0

There was a clear relationship between patients' choices and how they rated the reputation of their home hospital. Only 56% of those who classed their home hospital's reputation as "excellent" opted for an alternative hospital, while 75% of patients who rated the hospital as "fair", "poor", or "very poor" opted to go elsewhere ($p<0.05$) (Table 25).

Table 25: Views on home hospital reputation by choice (Group A)

Home hospital reputation	Chose home hospital (n=200) %	Chose alternative hospital (n=402) %
Excellent	43.9	56.1
Very good	39.7	60.3
Good	35.6	64.4
Fair	26.4	73.6
Poor	22.4	77.6
Very poor	26.5	73.5

6.2 Making the decision

Despite the fact that LPC guidance to OTs stated that all eligible patients should receive written information about the hospital choice project, less than two-thirds of Group B respondents (61%) recalled having received the LPC booklet *"Your guide to your choices"* while they were waiting for their operation. For many this would have been the first information they had received about the possibility of having their operation at an alternative hospital.

The next step in the process was supposed to be a telephone call or letter from a PCA based at the call centre. Most respondents recalled being contacted by a PCA to discuss their options, but more of those who had opted for treatment at an alternative hospital said they were contacted (89%) than those treated at their home hospital (80%). It is possible that respondents reporting no contact with a PCA may have been unaware that this was the title of the person they had spoken to.

For those who had no recollection of having received information about the LPC scheme, the first contact from the PCA came as a surprise:

> *"I got a call to say that you have "the right to choose." I'd never heard of it. I didn't know what she was talking about when she came on. I kept thinking what's she on about? Then she explained you know that it was a new thing and then I actually looked on the internet." (Interview B1: female, aged 60, had hip replacement at NHS treatment centre)*

Most Group B survey respondents (92%) reported that they had been given a choice of hospital while they were waiting for surgery. Of these, 79% opted for treatment at an alternative provider. Just over half (53%) said they had been offered a choice of staying at their home hospital or going to one of two alternatives. A third (33%) reported that they had been offered only one alternative and 9% said they were offered three or more. Just over 5% could not remember how many choices they were offered. Recall problems may have influenced these results. Because the decision about where to undergo treatment was often made within a single telephone conversation, it is possible that some patients, especially those who opted to stay at their home hospital, did not recall having contact with a PCA, being offered a choice, or the exact number of choices they were offered.

The proportion of Group B survey respondents who received treatment at an RT was higher than that in Group A, mainly due to the biased pattern of responses to the second questionnaire (see above, section 3.1). Table 26 gives a breakdown of the specific choices made by those in Group B: 21% stayed at their home hospitals and the remainder went elsewhere. Of those who opted for an alternative, the majority (82%) were treated in specially designated NHS treatment centres, while smaller proportions had their operations in ordinary NHS surgical departments (13%) and private hospitals (5%). Only one patient in the study received their treatment at a hospital overseas.

Table 26: Hospitals chosen (Group B)

Choice of hospital	**Frequency (n=894)** **%**
University College Hospital*	27.1
Home hospital	20.9
Moorfields St Ann's*	11.2
The ACAD Centre*	11.1
Other NHS hospitals	10.0
Ravenscourt Park Hospital *	8.1
Royal National Orthopaedic Hospital*	7.8
Private hospitals+	3.9

**NHS treatment centre; + Includes one patient treated at an overseas hospital*

Most Group B respondents said they had secured the option they wanted, but patients treated at their home hospital were slightly more likely to report that they got their first

choice of hospital (91%, compared to 89% of patients treated at alternative hospitals, p<0.001,Table 27). When those treated at RTs were asked to indicate why they had not been given their first choice, only a small proportion believed it was because they had been excluded on clinical grounds (0.7%) or because their operation was cancelled by the hospital (1.6%). The remainder attributed it to other reasons. These may have included, for example, that the patient had wanted to be treated at a hospital other than those they were offered, or that they would have preferred to undergo treatment at their local (home) hospital but the waiting time for surgery had been too long.

Table 27: Treated at first choice of hospital (Group B)

	Were you treated at your first choice of hospital?			
	Yes %	No, not suitable for treatment there %	No, operation postponed/cancelled %	No, another reason %
Treated at home hospital (n=178)	91.0	3.4	2.8	2.8
Treated at alternative hospital (n=679)	88.7	0.7	1.6	9.0
Total (n=857)	89.1	1.3	1.9	7.7

Patients gave positive reports on the quality of service provided by the PCAs: over 93% rated it as "good", "very good", or "excellent". Although not all patients felt it was necessary to keep in touch with their PCA about their treatment, those who did want to found it easy to do so (73%) and were positive about the support they received:

> *"Despite the Patient Choice thing supposed to be accelerating the process, nothing was happening from the hospital with them getting their act together. They had to be chased up by Patient Choice. They were good at chasing up when there was the problem". (Interview B8: male, aged 56, had hernia operation at an alternative NHS trust)*

Most survey respondents were satisfied with the support they were given during the process of making a choice, but some felt pressurised to make an instant decision and others were critical of the amount and quality of information provided:

> *"It was just two names and I said 'Where are they?' They said one was somewhere in the west of London and the other one was off the Tottenham Court Road and I went "I think I'll go to the UCH". That was literally the only information. There was no*

package or anything like that. There was no 'Oh that one's got a better this or that'- there was none of that." (Interview B2: male, aged 59, had hernia operation at an NHS treatment centre)

"They (the PCA) didn't seem to know much about the hospitals I was going to. When I asked questions – they didn't know. I think they came from Croydon. All they were saying was do you want this, or do you want that? They didn't know anything else." (Interview B3: female, aged 69, had hip replacement at an NHS treatment centre)

"Well I was contacted and asked to go to other hospitals. Yeah it was done too quick. I'm very afraid of hospitals, so when I have to go in hospital I like to get some idea of when I'm going in. But I was offered to go to the [NHS Trust] and I was offered to go to [NHS Treatment Centre] for this operation that I had in November, but it was too quick. It was sort of 'Would you like to go now?' It's very good for some people who are not scared, but not for me. So I rejected both occasions and stayed and went to [Trust II] for my operation." (Interview B10: male, aged 57, had hernia operation at Trust II)

Many of the interviewees who had declined the offer of choice said they had been given insufficient information to enable them to make an informed decision. Some said they were given the names of alternative hospitals, but no information about likely waiting time. Some patients' comments revealed misunderstandings about how the scheme worked. One patient expressed the fear that if they had agreed to change hospitals they would have had to go back to the beginning of the waiting list, resulting in an even longer wait. Others wanted more specific information about the clinical details of their operation than the PCA was able to provide. Some felt they had not been given sufficient time to consider their options or seek additional information.

Following contact with the PCA, many patients discussed their options with friends and family members. Issues that had been identified as important by Group A respondents before having been offered a choice – good clinical outcomes, clean environment, reputation of the surgeon and the hospital, continuity of care, and shorter waiting times – were still pertinent to those in Group B when faced with a real choice, but practical issues featured even more strongly. Convenience and familiarity were of even greater importance to some interviewees than having their operation quickly. Some were concerned that going to a more distant hospital might cause difficulties for their families, while others were primarily concerned about travel arrangements:

"I did discuss it with my family. Both my daughters are single mothers. I said no, because it's going to inconvenience people. Nobody finishes work before half past five, and travelling over to the other side of London could take a couple of hours. It's too far for people to travel, the cost involved, the time factor. I couldn't put my two daughters through that." (Interview B4: female, aged 77, had hip replacement at Trust IV)

"I wouldn't drive to London because there's nowhere to park. It's horrendous driving in London and I wasn't going to pay for the train and I knew I'd have to go into London for the pre-assessment and as it happens, the post-op. It takes all the worry out of getting anywhere if you know that someone's going to pick you up who knows where to go. Also it would cost about £5.00 return to go to London on the underground at certain times, especially before 10 o'clock and especially older

people, they can't afford it.!" (Interview B1: female, aged 60, had hip replacement at NHS treatment centre)

Three-quarters (75%) of those in Group B who had opted for their home hospital had received previous treatment at that hospital (Table 28). As might be expected, a previous history of treatment at the hospital was significantly less likely to be reported by patients treated at alternative hospitals ($p<0.001$). However, 6% of patients treated at RTs had been there before, and this may have influenced their decision to undergo surgery there on this occasion. Some interviewees said they had chosen to remain at their home hospital because they felt they would be better off remaining at the place where the staff knew their medical history.

Table 28: Previous experience of this hospital (Group B)

	Treated at home hospital (n=182) %	Treated at alternative hospital (n=701) %	Total (n=883) %
Received previous treatment at this hospital on one or more occasion	74.7	5.6	**19.8**
No previous treatment at this hospital	25.3	94.4	**80.2**

Some of those who had chosen to remain at their OT said they had heard criticisms of the hospital, but had discounted these because their own previous experience had been positive. In contrast, interviewees who accepted the offer of an alternative were often quite critical of their home hospital:

"I got offered hospitals all over the place. I got letters saying they'd transport me and my carer and they would do all that but I really wasn't interested in going far away because firstly I'm very home orientated, like I like to be at home, I like to be near my own, I'm happier at home. Also that hospital up there is as far as I'm concerned the best in the world so what's the point in travelling off. Okay it could have been done much quicker but I was much happier to stay at home." (Interview B1: female, aged 47, had varicose vein operation at Trust I)

"I just thought if I can get the operation done more quickly it can't be any worse than [NHS Trust]. I suppose there's neglect in some way but if the resources aren't there you can't run a hospital efficiently." (Interview B10: female, aged 58, had varicose veins operation at NHS treatment centre)

Given the considerable amount of media coverage on the prevalence of MRSA and other 'superbugs', it was no surprise to find that concerns about infection risk were uppermost in the minds of many of the interviewees. Many sought the advice of friends with medical knowledge on this point:

"A friend of mine is a nurse at [NHS Trust] and she said "Go to [NHS Treatment Centre], there's no MRSA". So I decided on that. I didn't mind how many miles I travelled – I would travel to the end of the world just to get a hospital that didn't have that infection." (Interview B3: female aged 69, had hip replacement at NHS treatment centre)

For others, the offer of treatment at a well-known hospital with a good reputation was a key factor in persuading them to accept the alternative:

"Everybody in London knows about [NHS Treatment Centre], it does a lot of research and it's a leading place for cancer of the bones and things like that and it's just got a great reputation." (Interview B1: female, aged 60, had hip replacement at NHS treatment centre)

Some patients wanted more than just a choice of hospital. They also wanted to be able to specify who would carry out their operation. Those who wanted to be treated by a specific surgeon did not always receive reassurance that their preference would be respected:

"I think, they said "A private hospital had been taken over for so many weeks to do hip replacements". And I said did they know if my consultant would be there? And they didn't know who it would be done by." (Interview B9, female, aged 70, had hip operation at Trust III)

"I had already been treated by the surgeon the year before, so rather than go to a strange hospital, strange doctor, I thought the one that you know sometimes is always the safest. So I went to see him. I chose to wait." (Interview B7: female, aged 74, had knee operation at Trust V)

"The Consultant had been recommended to me. I asked my GP if I could have an appointment with him, which I had. [My friend's] mother had had hip replacements and done very well." (Interview B9: female, aged 70, had hip replacement at Trust III)

Many patients found making a choice quite difficult. Some interviewees felt they were unqualified to judge the quality of care provided by individual doctors:

"I'm too ignorant really. It wouldn't be fair for me to make any sort of judgment. You can never judge a person can you. It's more than you dare do to publish anything saying whether he is a good surgeon or he is a bad surgeon. I'm a layman so to me they are just qualified." (Interview B8: male, aged 74, had knee replacement operation at Trust I)

Very few patients said they had felt pressurised to make a specific choice: 2% of patients treated at their home hospital and 3% of those treated at an alternative hospital said they had felt under some pressure. However, some patients' choices had been influenced by discussions with particular people (Table 29). One in five (20%) of those treated at an alternative hospital said they had been influenced by the PCA and 16% said their family and friends exerted an influence. Patients treated at their home hospital were significantly less likely to say that others had influenced their decision.

Table 29: People who influenced patients' choice (Group B)

Person who influenced choice	Treated at home hospital (n=182) %	Treated at alternative hospital (n=707) %
GP	8.2	3.0
Doctor at home hospital	4.4	2.7
Doctor at another local hospital	1.6	1.1
PCA	7.1	19.5
Family or friends	9.3	16.1
Someone else	1.1	1.7
Not influenced by anyone	66.5	56.4

Although issues linked to safety and quality of care (hygiene, success rates, experience of surgeon etc.) were rated as very important by a majority of survey respondents, it was apparent that many patients assumed there would be little variation in the quality of clinical care between hospitals. While some thought that all hospitals would be equally good, especially in relation to clinical care, others had relatively low expectations of any hospital. In either case, when making a decision patients tended to place greatest emphasis on issues such as where the hospital was located, length of wait for the operation, travel arrangements and convenience for family and friends, perhaps because these were the issues on which they felt most competent to make a judgement.

7 Patients' information needs

The study enabled an examination of patients' information needs, both while making a decision about where to be treated, and during their time on the waiting list. It was clear that patients required various types of information at different stages in the process, both to assist them in making informed choices and to help them through the process of care. Patients' information requirements are described below, together with their assessments of the extent to which they had been able to obtain the information they wanted.

7.1 Information to support decision-making

Group A survey respondents were asked to indicate the three most important items of information that they would need to know when offered a choice of hospital (Table 30). The location of the hospital was mentioned most frequently, reflecting patients' concern about how they would get there, whether it would be convenient for their visitors, and so on. The hospital's reputation and its success rates in carrying out the particular operation the patient was due to undergo also ranked high.

Table 30: Information required before choosing a hospital (Group A)

Information required	(n=1,715) %
Location of hospital and how to get there	55.2
Success rates for operation	50.0
Reputation of the hospital	47.0
Who will perform the operation	27.3
How clean the wards are	20.6
What type of hospital (private/NHS/teaching)	20.2
How long I will have to stay	18.2
Whether a friend or family member can stay with me	12.7
What the staff are like	3.1
Visiting hours	3.1
What the surroundings/facilities are like	2.9
What the food is like	0.9

Many respondents wanted to know about standards of cleanliness and hygiene, stressing the risk of infection as a major concern:

> *"Its reputation and its hygiene, that sort of thing. Because I've got a friend who unfortunately has been in [Trust IV] and contracted the MRSA and she's very bitter about it. That is something that really needs to be addressed." (Interview A4: female aged 62, waiting for knee operation)*

Some also wanted information about the experience and qualifications of the surgeon responsible for their treatment and the hospital's track record in carrying out the procedure they were waiting for, including numbers performed and outcomes:

> *"The number of successful hip operations that were undertaken at the other hospital." (Interview A14: female aged 63, waiting for hip operation)*

> *"One would like to know something about their reputation and so on and so forth and how successful they've been." (Interview A17: male aged 85, waiting for knee replacement)*

"What's the survival rate?" (Interview A15: male aged 67, waiting for hernia repair)

The *Before Surgery* questionnaire asked patients where they would expect to find information about alternative hospitals (Table 31).

Table 31: Preferred information sources (Group A)

	(n=1,715)* %
GP	67.3
Doctor at home hospital	39.9
Internet	36.3
NHS Direct	24.6
Doctor at alternative hospital	23.0
Family or friends	19.3
Library	4.9
Newspapers	4.3
Somewhere else	2.3

** Excludes those who would not consider going to an alternative hospital*

Most said they would turn to their GP for information or to a doctor at their home hospital, but more than a third said they would look for information on the internet. Not surprisingly, this information source was much more commonly mentioned by those aged under 60 (51%) than by those in the older age-group (19%) ($p<0.001$). There was also a difference between the age-groups in the likelihood of mentioning NHS Direct as a preferred source of information, with 27% of the younger age-group citing it as a possible source of information compared to 22% of the older age-group ($p<0.05$). Younger patients were more likely to seek information from their family and friends, newspapers and library sources. The sources more likely to be preferred by patients aged over 60 were their GP (71% compared to 65% of those in the younger group, $p<0.01$), and doctors based at the alternative hospitals (26% compared to 21%, $p<0.05$).

Group A survey respondents were asked who they would want to discuss their hospital choices with (Table 32). Most said they would talk to their GP in the first instance, but the notion of a special telephone helpline also received some support.

Table 32: Who would you like to discuss your options with? (Group A)

	(n=1715)* %
GP	63.7
Doctor at home hospital	49.3
Doctor at alternative hospital	32.8
Family or friends	23.4
Special telephone helpline	15.9
Someone else	1.5

** Excludes those who would not consider going to an alternative hospital*

Some of the interviewees said they would rely on family members to find information for them about the hospitals, while others, particularly older people, found the question more challenging, saying they would find it difficult to know where to find the type of information they would need. Many said they would turn to their GPs for help:

> *"Get my husband on the Internet and find out like that really." (Interview A6: female aged 47, waiting for gall bladder operation)*

> *"That's not easy for a private citizen. I would have to go to the library and ask had they got any information on hospitals or wherever it was. But actually if it was north London I wouldn't have much access to information on anything other than in this area." (Interview A7: female aged 83, waiting for knee operation)*

> *"My own GP and the GP surgery are the first port of call. They're a patients' main contact with the rest of the medical professions. I mean you don't walk up to [Trust III], bang on the consultants' door and say 'Are you any good?'" (Interview A25: male aged 63, waiting for hernia repair)*

There were some significant differences between ethnic groups, both in their preferred sources of information about different hospitals, and in who they would like to discuss their options with. Most strikingly, respondents from non-white groups were significantly more likely to look to their family and friends for information about hospitals: 28% indicated that they would use family and friends as an information source, compared to only 17% of white respondents ($p<0.001$).

Although only a small percentage of the total sample (5%) indicated that they would look to the library for relevant information, this was higher among people from minority ethnic groups (8%) than among white respondents (4%) ($p<0.05$).The only source of information

that was felt to be more useful by white than non-white respondents was a doctor at the alternative hospital (24%, compared to 18%) ($p<0.05$).

In terms of who patients felt they would like to discuss their options with if they were offered a choice of hospital, the findings were similar. Patients from ethnic minorities were again more likely to want to talk to their family and friends, with 31% selecting this option, compared to 23% of white respondents ($p<0.01$). Patients in minority ethnic groups were also significantly more likely to want to discuss their options with their GP, with just over three quarters saying they would do so (76%) compared to 62% of white patients ($p<0.001$).

The *After Surgery* questionnaire asked patients about the information they had obtained when making the decision about where to be treated. The PCA was the main source of advice about the different hospitals for 65% of respondents in Group B, but some said they sought information from family and friends (7%) or from NHS Direct (8%). Despite their stated intentions prior to surgery, only 3% had consulted their GP for advice about the options and a further 3% had sought advice from a doctor at their home hospital. This discrepancy between what they said they would do beforehand and what they actually did when offered a real choice might indicate that the PCA's advice was considered adequate, or alternatively that patients were unable to seek other forms of advice because they felt they had to make a quick decision.

Those treated at their home hospital were significantly less likely to cite either their PCA or their family and friends as their main source of information ($p<0.001$). These people were more likely to say they did not get any information about alternative hospitals (17%) compared to those treated at RTs (9%). Nearly two-thirds of Group B respondents said that, overall, they had received sufficient information about their options to make a decision (63%), while 16% of patients who were offered a choice said they did not require any information about the alternatives.

Patients were asked to consider a number of different items of information and to say whether they had received sufficient information about each, using the following response categories: "Yes, definitely", "Some, but not enough", "I wanted information but did not get any" and "I did not want/need information" (Table 33). Most respondents were happy with the information they had received about hospital location and travel arrangements, but many were dissatisfied with the amount of information they had been given in relation to arrangements for follow-up care, the quality of care in the different hospitals, the qualifications and experience of the surgeons, operation success rates, standards of hygiene and safety record. The three areas of information considered least important (i.e. those with the highest proportion of respondents saying "I did not want/need information") were size of wards, car parking facilities, and visiting hours at the different hospitals. However it is important to recognise that some patients *did* want to know about these issues.

Table 33: Did you receive enough information? (Group B)

Factor	n	Yes, definitely %	Some, but not enough %	I wanted information but did not get any %	I did not want/need information %
Travel arrangements and how I would get to the different hospitals	832	74.3	10.9	3.1	11.7
The location of the different hospitals	831	70.4	11.1	2.8	15.8
How long I would have to wait for my operation at the different hospitals	788	62.8	15.7	7.0	14.5
How long I would have to stay at the different hospitals	798	59.4	14.3	5.6	20.7
The hospitals' experience of treating people with my condition	801	45.3	11.2	11.5	32.0
Arrangements for follow up care at the different hospitals	792	44.9	14.3	15.3	25.5
The quality of patient care in the different hospitals	775	34.1	11.6	16.0	38.3
The qualifications and experience of the surgeons at the different hospitals	786	32.7	10.8	16.8	39.7
The success rates in the different hospitals for the operation I was having	789	32.3	11.7	15.6	40.4
The standards of hygiene at the different hospitals	777	30.6	10.6	17.6	41.2
The visiting times at the different hospitals	783	30.3	7.7	8.8	53.3
The safety record of the different hospitals (e.g. errors, infections etc)	772	24.0	11.4	19.6	45.1
The car parking facilities at the different hospitals	773	22.6	8.7	9.6	59.1
The size of the wards at the different hospitals	779	18.1	8.5	10.7	62.8

Patients treated at RTs were much more likely to be satisfied with the information they had received. but even in this group there were significant gaps between what was wanted and what they actually received (Table 34). More than a third said they did not receive sufficient information about the quality of care in the different hospitals.

Table 34: Proportion of patients who were satisfied with information (Group B)

	Treated at home hospital (n= 161) %	Treated at alternative hospital (n=665) %
Travel arrangements and how I would get to the different hospitals	60.8	87.6
The location of the different hospitals	67.0	86.5
How long I would have to wait for my operation at the different hospitals	50.5	77.7
How long I would have to stay at the different hospitals	44.9	79.8
The hospitals' experience of treating people with my condition	35.7	72.2
Arrangements for follow up care at the different hospitals	24.1	65.9
The quality of patient care in the different hospitals	21.1	61.2
The qualifications and experience of the surgeons at the different hospitals	27.8	59.0
The success rates in the different hospitals for the operation I was having	25.7	59.6
The standards of hygiene at the different hospitals	18.8	58.0
The visiting times at the different hospitals	41.0	69.5
The safety record of the different hospitals (e.g. errors, infections etc)	22.5	47.9
The car parking facilities at the different hospitals	36.2	59.7
The size of the wards at the different hospitals	22.0	54.2

**Excludes patients who did not require information.*

There was a relationship between the hospital chosen by the patient and whether or not they required information when they were offered a choice. Many respondents who were apparently unwilling to consider alternatives to their home hospital, said they did not require particular items of information (Table 35).

Table 35: Proportion of patients who did not want information (Group B)

	Treated at home hospital (n=171)	Treated at alternative hospital (n=665)
Travel arrangements and how I would get to the different hospitals	41.9	4.1
The location of the different hospitals	38.0	10.0
How long I would have to wait for my operation at the different hospitals	35.2	9.1
How long I would have to stay at the different hospitals	45.4	14.3
The hospitals' experience of treating people with my condition	49.7	27.3
Arrangements for follow up care at the different hospitals	51.5	18.8
The quality of patient care in the different hospitals	55.9	33.7
The qualifications and experience of the surgeons at the different hospitals	55.8	35.5
The success rates in the different hospitals for the operation I was having	55.7	36.3
The standards of hygiene at the different hospitals	57.1	37.0
The visiting times at the different hospitals	63.3	50.6
The safety record of the different hospitals (e.g. errors, infections etc)	56.4	42.0
The car parking facilities at the different hospitals	64.6	57.6
The size of the wards at the different hospitals	69.1	61.1

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Not surprisingly patients treated at their home hospital were more likely to say they had not needed information about practical things such as the location of the hospital, travel arrangements or car parking, but they were also less likely to feel a need for information about likely waiting times, length of stay, safety record, clinical quality or follow-up arrangements. Having made a decision to stay at the OT, many did not want to be bothered with these types of details:

> *"I said [to the PCA] that I had made up my mind really for this home hospital which is [Trust III] and I was reluctant really to go to some other hospital." (Interview B6: male, aged 67, had prostatectomy at Trust IV)*

"I didn't want to because I think that once you've already got something in your mind, that's where you want to go." (Interview B11: male, aged 58, had hernia operation at Trust III)".

However, of those patients who *did* require information about alternatives, those who ultimately chose to remain on the waiting list at their home hospital were significantly less likely to report that they had received enough information about each of the factors they were asked to consider. This suggests that some patients may have been unwilling to consider alternative hospitals because they had not been given sufficient information on which to base their decision.

"When I was offered an alternative hospital, it was very short notice. I wasn't given enough information and enough time to assimilate that information. People should be given a choice, with enough time to find out and so on. I had no idea even where the hospital was, at which county, which borough, which part of…whether England, Scotland, Wales, you know." (Interview B7: female, aged 74, had knee operation at Trust V)

7.2 Information while waiting for surgery

In order to assess the level of information and support patients felt they received after they had made their decision about where to be treated, Group B survey respondents were asked three questions:

- If you had any questions about **your operation** did you know who to contact?
- If you had any questions about **the hospital you had chosen** (e.g. parking, visiting hours) did you know who to contact?
- If you had any questions about **your admission to hospital** (e.g. appointment times, travel arrangements) did you know who to contact?

The results are detailed in Tables 36 – 38, which compare responses from those treated at their home hospital and those treated elsewhere.

Table 36: Did you know who to contact for questions about operation? (Group B)

	Treated at home hospital (n=177) %	Treated at alternative hospital (n=688) %	Total (n=865) %
Yes, definitely	50.3	58.1	56.5
Yes, to some extent	24.3	21.5	22.1
No	11.9	8.9	9.5
I did not have any questions	13.6	11.5	11.9

Table 37: Did you know who to contact for questions about hospital? (Group B)

	Treated at home hospital (n=174) %	Treated at alternative hospital (n=680) %	Total (n=854) %
Yes, definitely	33.3	49.9	46.5
Yes, to some extent	19.5	21.5	21.1
No	17.8	11.6	12.9
I did not have any questions	29.3	17.1	19.6

Table 38: Did you know who to contact for questions about admission? (Group B)

	Treated at home hospital (n=177) %	Treated at alternative hospital (n=684) %	Total (n=861) %
Yes, definitely	50.8	72.1	67.7
Yes, to some extent	17.5	17.3	17.3
No	9.6	3.8	5.0
I did not have any questions	22.0	6.9	10.0

There were no significant differences between the two groups in relation to questions about their operation: more than half were confident they knew who to contact, but 22% were only partly sure and 10% said they did not know. In the other two areas of concern it

seems that patients who opted for treatment at their home hospital required less support, i.e. did not need to ask questions. Concerns about the hospital itself and the admission process will clearly have a greater effect on patients who have selected an unfamiliar hospital, and who are going through a process which is still relatively new. However, where patients *did* require support during their time on the waiting list, it was more likely to be available to those patients who had opted for treatment at an alternative hospital. Patients who had chosen alternative hospitals and who had questions about the hospital facilities or about their admission were significantly more likely to say they knew who to contact ($p<0.001$), presumably because they knew they could refer any queries to the PCA service.

Patients who opted for treatment at an alternative hospital clearly benefited from the service provided by the team of PCAs, who fulfilled a useful intermediary role between the patient and the OTs and RTs. These patients reported a more positive experience of being on the waiting list than those who opted to stay at their home hospital. The relatively high proportion of respondents who were not clear who to contact about their concerns or queries highlights a wider problem affecting all patients on NHS waiting lists.[18]

18 Healthcare Commission. *Patient survey report 2004 – overview.* www.healthcarecommission.org

8 Going into hospital

Once patients had made a decision about where to be treated, all those who had been offered a choice were followed-up to compare the experiences of those who chose an alternative hospital and those who opted to remain at their home hospital.

8.1 Travel arrangements

Group B survey respondents were asked about the length of time it had taken them to get to the hospital where they had their operation, the type of transport they had used, and how comfortable and well-organised this had been. Not surprisingly, those who had opted for an alternative to their home hospital experienced significantly longer journeys than those who had been treated at their home hospital. Only 5% of patients treated at their home hospital had journey times of an hour or more, compared to more than half (54%) of those treated at an alternative hospital ($p<0.001$).

The offer of free transport to and from hospital was an integral feature of the LPC scheme, and this is reflected in the fact that the majority of patients treated at alternative hospitals used hospital transport. Overall, 25% travelled to hospital in an ambulance or other hospital transport, while 49% travelled in a taxi paid for by the hospital. The return journey showed similar patterns, with 23% of patients being taken home by ambulance and 51% being taken by a hospital-funded taxi. In contrast, the majority of patients treated at their home hospital made their own transport arrangements, travelling either by public transport or in a private car. Less than 4% of patients treated at their home hospital had transport to the hospital provided for them, although for the return journey this was noticeably higher, at 17%.

It was important not only that transport was well organised and comfortable, but that it was appropriate to the patient's needs. For example, a patient who had recently undergone hip replacement surgery might find the cramped conditions in a mini-cab extremely uncomfortable and would be clinically contraindicated for some patients if it increased the risk of dislocating the joint. On the other hand, it could be considered unnecessary to provide an ambulance for a patient who had undergone cataract surgery, for whom a taxi would be appropriate. There were wide variations in the type of transport provided by the various RTs (Table 39).

Table 39: Mode of transport to and from hospital (Group B)

Type of transport	Moorfields St Anns' (n=107)		Ravenscourt Park (n=78)		RNOH (n=77)		ACAD (n=105)		UCLH (n=252)		Other NHS (n=93)		Other Private (n=38)		Home hospital (n=212)	
	To	From	To	From	To	From	To	From	To	From	To	From	To	From	To	From
Ambulance/other hospital transport	87.9	90.7	30.8	15.4	50.6	37.7	8.6	2.9	1.6	3.6	11.8	16.1	13.2	15.8	1.9	13.7
Taxi (hospital paid)	1.9	0.9	30.8	42.3	5.2	6.5	68.6	59.6	81.7	87.3	44.1	38.7	50.0	50.0	1.4	3.3
Taxi (patient paid)	0.9	0.9	1.3	7.7	1.3	0	0	1.0	0	1.2	2.2	8.6	0	2.6	17.0	14.2
Other public transport (patient paid)	0.9	0	10.3	2.6	0	0	1.9	0	13.9	2.4	22.6	5.4	13.2	2.6	14.2	4.3
Private car	3.7	4.7	21.8	30.8	42.9	55.8	20.0	33.7	1.2	5.2	18.3	30.1	21.1	26.3	62.3	63.0
Other	4.7	2.8	5.1	1.3	0	0	1.0	2.9	1.6	0.4	1.1	1.1	2.6	2.6	3.3	1.4

Moorfields St Ann's provided an ambulance or other hospital transport for nearly 90% of patients' journeys to hospital, and just over 90% of return journeys. University College London Hospital (UCLH) favoured taxis paid for by the hospital, providing these for 82% of patients' journeys to hospital, and 87% of return journeys. The ACAD centre was similar, providing taxis to hospital for 69% of patients, and taxis home for 60%. Like Moorfields St Ann's, the Royal National Orthopaedic Hospital (RNOH) made greater provision of ambulances or other hospital transport: this mode of transport was provided for 51% of patients' journeys to hospital and 38% of return journeys. RNOH had an unusually high incidence of patients returning home by private car after their hospital stay at 56%, as compared to 34% of ACAD patients and 31% of those treated at Ravenscourt Park. In contrast, only 5% of patients treated at UCLH and Moorfields St. Ann's travelled by private car.

Regarding the journey to hospital, most patients who had transport provided for them, either in the form of an ambulance or a taxi, were highly satisfied with the arrangement: 83% of those who travelled by ambulance or taxi said the transport was well organised, compared to only 74% of those who travelled by public transport ($p<0.001$).

In relation to the return journey, patients who were transported by taxi were less likely than those transported by ambulance to report the transport as "very well organised" (77%, compared to 82%; $p<0.001$). Very few patients treated by RTs had to make their

own transport arrangements, and again these were the least satisfied, with 74% of those who travelled home by private car saying the transport was well organised.

When asked about comfort, it was patients who travelled to hospital by private car who were most likely to report the journey as being "very comfortable" (77% compared to 73% of those who travelled in a taxi paid for by the hospital and 71% who travelled by ambulance; $p<0.001$). However, when asked about comfort during the return journey, patients who travelled by ambulance were the most comfortable: 74% regarded their journey as "very comfortable" compared to less than two thirds of patients who travelled by taxi paid for by the hospital or private car (64% and 63% respectively; $p<0.001$).

The provision of free transport was one of the most popular aspects of the scheme. However, some interviewees were critical of the transport arrangements. In some cases it had arrived late and caused them to miss their appointments. Others felt that the wrong type of transport had been provided:

> *"They organise transport for us and that is chaotic! On one occasion there were six of us packed into a five-seater which I found dangerous…and the other one the driver kept going to sleep at 80 miles an hour on the A13. I've rung them on one occasion and said "Is this vehicle on it's way?" And all it's done is increased his speed to get here and increased the stress of the passengers" (Interview B12: male, aged 73, had cataract operation at NHS treatment centre)*

> *"That was awful! It's about a two hour drive from here and the transport was four hours late, so I had to ring up and cancel the appointment and they said "Sorry about that we'll send you another one", but the other one was late. So instead of doing the morning session, I ended up in the afternoon session." (Interview B3: female, aged 69, had hip replacement at NHS treatment centre)*

> *"I came home in the middle of rush hour, a few days after my operation in an ordinary taxi. The driver was as kind as he possibly could have been, but it really shook my hip up because it was just an ordinary car. That should have been sacrosanct, that you had more comfortable transport when you'd had the operation…..One old gentleman that went up in the transport with me, we had to look after him because he just wasn't 'able' and then another lady was really ill when we picked her up and she was kind of falling against me in the car. I don't quite know what happened to them. I think it's traumatic to send somebody out of area." (Interview B6: female, aged 68, had hip replacement at NHS treatment centre)*

In many cases travel was arranged for carers as well as for the patient themselves: 52% of those treated at alternative hospitals said transport was arranged for a friend or family member, compared to 23% of those treated at their home hospital ($p<0.001$). However, 40% of those treated at RTs and 64% of those treated at OTs said that travel arrangements for family or friends had not been necessary (Table 40). Despite the differences in the two groups' experience, they were equally satisfied with the travel arrangements for their carers: 92% said they were definitely satisfactory, 7% said they were satisfactory "to some extent", and only 2% said they were not satisfactory.

Table 40: Transport arrangements for family? (Group B)

	Treated at home hospital (n=179) %	Treated at alternative hospital (n=686) %	Total (n=865) %
Yes	23.5	52.0	46.1
No, but I would have liked it	12.3	7.9	8.8
It was not necessary	64.2	40.1	45.1

8.2 The hospital stay

Thirty questions from the national NHS inpatient survey were included in the *After Surgery* questionnaire to assess the quality of care received and to compare the experience of those who opted to go to an alternative hospital with that of patients who opted to stay at their home hospital. The results are shown in Tables 41 – 60.

Patients in Group B who had opted to go to an alternative hospital were less dissatisfied with the length of time they had waited for surgery than those treated at their home hospital. Nearly two thirds (63%) of patients who opted for treatment at their home hospital felt they should have been admitted to hospital sooner than they were, compared to just under half (48%) of patients treated at an alternative hospital ($p<0.001$, Table 41).

Table 41: Views on waiting time (Group B)

	Treated at home hospital (n=184) **%**	**Treated at alternative hospital (n=682)** **%**	**Total (n=866)** **%**
Admitted at right time	37.5	52.1	49.0
Should have been admitted a bit sooner	33.7	29.2	30.1
Should have been admitted a lot sooner	28.8	18.8	20.9

While most respondents were satisfied with the amount of notice they had been given about their admission date, patients who opted for treatment with an alternative provider were slightly more satisfied than those treated at home hospitals ($p<0.05$, Table 42).

Table 42: Sufficient notice of date of admission? (Group B)

	Treated at home hospital (n=185) %	Treated at alternative hospital (n=694) %	Total (n=879) %
Yes, enough notice	94.6	97.7	97.0
No, not enough notice	5.4	2.3	3.0

There were some concerns among those who chose to go to alternative hospitals about coordination of care between OTs and RTs. Two interviewees who attended an RT for a pre-op assessment were referred back to their OT because of clinical concerns. As a consequence one felt she was "caught in the middle" of the two hospitals' systems:

> *"I think it's really important that the communication between the hospitals is much tighter than in any other set of circumstances. I should have had a pre-operative assessment at [Trust IV] before I was even sent right up to [NHS Trust]. Hopefully I would have been seen fairly quickly and the blood thing and the heart would have been picked up at the same time. I kind of felt that once [Trust IV] had gone into the Patients Choice, [Trust IV] abandoned me. I think you've got to give a much bigger back-up to the scheme otherwise people get lost". (Interview B6: female, aged 68, had hip replacement at NHS treatment centre)*

The same patient was distressed because her notes did not arrive at the alternative hospital and staff handled the problem in an insensitive manner.

> *"I was sent to [NHS Trust] and when I got there we were sitting waiting for two hours…and somebody came to us and said 'We can't see you because your notes aren't here'. I don't know whose fault it was but my notes didn't arrive and then we were seen by this other nurse or sister and she said 'Oh well you can't be seen, I don't know why they're sending you here, we've got enough patients on our own waiting list!' My friend and me felt very, very rejected." (Interview B6: female, aged 68, had hip replacement at NHS treatment centre)*

This type of incident was relatively rare, however. Most patients were very satisfied with the way they were cared for and with communications with hospital staff.

Both patients treated at their home hospital and patients treated at an alternative hospital were equally likely to report that doctors and nurses answered any questions they had in a way they could understand. However, patients treated at RTs reported more positive experiences in two areas: they were more likely to express confidence and trust in the doctors and nurses treating them and they were more likely to feel that the doctors knew enough about their condition ($p<0.05$) (Tables 43-45).

Table 43: Confidence and trust in doctors? (Group B)

	Treated at home hospital (n=187) %	Treated at alternative hospital (n=698) %	Total (n=885) %
Yes, always	85.6	91.4	90.2
Yes, sometimes	13.9	7.2	8.6
No	0.5	1.4	1.2

Table 44: Confidence and trust in nurses? (Group B)

	Treated at home hospital (n=187) %	Treated at alternative hospital (n=698) %	Total (n=885) %
Yes, always	79.7	87.4	85.8
Yes, sometimes	17.6	11.2	12.5
No	2.7	1.4	1.7

Table 45: Did doctors know enough about condition or treatment? (Group B)

	Treated at home hospital (n=186) %	Treated at alternative hospital (n=695) %	Total (n=881) %
All knew enough	78.5	84.9	83.5
Most knew enough	9.1	8.8	8.9
Some knew enough	4.8	1.2	1.9
None knew enough	1.1	0.4	0.6
Can't say	6.5	4.7	5.1

Overall, just under three-quarters of respondents (74%) felt they were sufficiently involved in decisions about their care and treatment, but this proportion was higher among patients who were treated at an alternative hospital (76%) than among those treated at their home hospital (66%) ($p<0.05$, Table 46).

Table 46: Involvement in decisions about care and treatment? (Group B)

	Treated at home hospital (n=185) %	Treated at alternative hospital (n=694) %	Total (n=879) %
Yes, definitely	65.9	75.5	73.5
Yes, to some extent	27.0	21.6	22.8
No	7.0	2.9	3.8

It is worth noting that patients who opted to undergo their operation at a hospital other than the one where they were originally placed on a waiting list had already taken a significant step towards greater involvement in their own care. It is possible, therefore, that these patients were a distinct group, inherently more confident about participating in decision-making or more able to articulate their views to clinicians.

Overall, nearly 90% of patients reported that they were given enough information about their treatment. There was no significant difference between the experiences of patients treated at OTs and patients treated at RTs in this respect. Similarly, around one in ten patients (11%) said they could not find anyone on the hospital staff to talk to about their worries or fears. This proportion was similar in both groups.

However, when asked to provide detail about the information they had received from hospital staff, patients treated at RTs reported more positive experiences. These patients were more likely to say they had received an explanation of what would be done during their operation ($p<0.05$), that the risks and benefits of the operation had been explained to them ($p<0.001$), that they were given accurate information about how they would feel afterwards ($p<0.001$), and that after the operation someone explained to them how it had gone ($p<0.001$) (Tables 47-50).

Table 47: Clear explanation of operation procedure? (Group B)

	Treated at home hospital (n=186) %	Treated at alternative hospital (n=693) %	Total (n=879) %
Yes, completely	69.4	78.4	76.5
Yes, to some extent	23.7	17.6	18.9
No	4.3	1.9	2.4
I did not want an explanation	2.7	2.2	2.3

Table 48: Clear explanation of risks and benefits of operation? (Group B)

	Treated at home hospital (n=184) %	Treated at alternative hospital (n=692) %	Total (n=876) %
Yes, completely	64.7	75.9	73.5
Yes, to some extent	27.7	15.2	17.8
No	3.8	5.1	4.8
I did not want an explanation	3.8	3.9	3.9

Table 49: Clear explanation of how you would feel afterwards? (Group B)

	Treated at home hospital (n=183) %	Treated at alternative hospital (n=687) %	Total (n=870) %
Yes, completely	44.8	60.8	57.5
Yes, to some extent	37.2	26.3	28.6
No	18.0	12.8	13.9

Table 50: Clear explanation of operation outcome? (Group B)

	Treated at home hospital (n=183) %	Treated at alternative hospital (n=692) %	Total (n=875) %
Yes, completely	50.3	69.1	65.1
Yes, to some extent	32.8	20.7	23.2
No	16.9	10.3	11.7

While it is possible that staff in treatment centres or private hospitals were better trained or had more time for dialogue with patients, it could also be the case that patients who chose alternative hospitals were more pro-active in seeking out information about all aspects of their care and were more naturally inclined to ask questions. Interestingly, when survey respondents were asked if their questions had been answered by staff, there was no significant difference between the two groups, demonstrating that when patients treated at their home hospital *asked* for information, they did receive it.

There were some complaints about lack of cleanliness by interviewees treated at OTs. Several people complained of dirty toilets and patches of blood on the floor. Some went to considerable lengths to protect their own safety by ensuring that staff complied with safe hygienic practices:

> *"A nurse wanted to change my dressing without wearing gloves. When I explained that I was worried about contracting an infection, the nurse said that this was not necessary as she would not be touching the wound, only the dressing. I protested and the nurse eventually got some gloves. Also I saw a nurse that had used gloves to change a patient's dressing take them off and put them on the patient's side table. Hygiene was one of my main concerns and it would have been helpful to have had a written leaflet on hygiene for the patient." (Written comment from Group B survey respondent)*

In contrast, interviewees who accepted the offer of an alternative hospital were more likely to comment positively on its cleanliness:

> *"I mean I could just recommend it to anyone – the nursing staff, the cleanliness. They test you for MRSA so if you have got it, or carry it they don't want you which is fair enough. It was a brilliant hospital, incredible! The consultants came to see you every single day… incredible! You had your own nurse, she looked after you and so when they came round like the house doctors to see you, they wanted to look at the wound but they wouldn't touch you. The nurse with her gloves on let them see the wound and they would look at it. She would then take the gloves off and wash her hands but they would never touch you and walk away to another patient. I mean the cleanliness there was just incredible and the sheets were changed every day – sometimes twice a day. They had so much staff …it was brilliant!". (Interview B3: Female, aged 69, had hip replacement at NHS treatment centre)*

One in ten survey respondents felt that hospital staff had not spent enough time telling them what would happen during their recovery at home, and two in ten felt that their family or home situation was not taken into account when they were discharged. Once again those treated at RTs reported more positive experiences. They were more likely to have been given information about who to contact if they had any worries after leaving hospital ($p<0.05$), more likely to say that they had been given written or printed information about what they could or could not do after leaving hospital ($p<0.001$), more likely to have been given information about danger signals to watch for after returning home ($p<0.001$), and more likely to have been told when to resume their usual activities ($p<0.01$) (Tables 51-54).

Table 51: Information about who to contact after discharge? (Group B)

	Treated at home hospital % (n=177)	Treated at alternative hospital % (n=644)	Total % (n=821)
Yes	80.8	87.1	85.7
No	19.2	12.9	14.3

Table 52: Given written information about recovery? (Group B)

	Treated at home hospital (n=185) %	Treated at alternative hospital (n=687) %	Total (n=872) %
Yes	74.6	86.9	84.3
No	25.4	13.1	15.7

Table 53: Told about danger signals to watch for? (Group B)

	Treated at home hospital (n=182) %	Treated at alternative hospital (n=687) %	Total (n=869) %
Yes, completely	38.5	50.9	48.3
Yes, to some extent	23.1	18.0	19.1
No	29.7	18.8	21.1
It was not necessary	8.8	12.2	11.5

Table 54: Told when to resume usual activities? (Group B)

	Treated at home hospital (n=181) %	Treated at alternative hospital (n=674) %	Total (n=855) %
Yes, completely	48.1	60.8	58.1
Yes, to some extent	32.0	23.0	24.9
No	19.9	16.2	17.0

Patients treated at their home hospital were more likely to feel they had been discharged from hospital too early (19% compared to 11% of patients treated at an alternative hospital) ($p<0.01$) (Table 55). This might be because patients treated at RTs had more realistic expectations of length of stay, due to the fact that they had received more information about the treatment process.

Table 55: Views on timing of discharge (Group B)

	Treated at home hospital (n=185) %	**Treated at alternative hospital (n=682) %**	**Total (n=867) %**
Too early	18.9	10.7	12.5
At the right time	81.1	87.8	86.4
Too late	0	1.5	1.2

Patients treated at RTs and OTs were equally likely to experience delays when being discharged from hospital. Overall, one in five patients experienced delays to their discharge (20%). However, patients treated at RTs were significantly more likely to experience delays due to waiting for transport (33%, compared to 7% of those treated in their home hospital), while the main reason that patients at OTs experienced delays was that they had to wait for medication (42% of home hospital patients compared to 24% of patients treated at alternative hospitals) ($p<0.01$) (Table 56).

Table 56: Reasons why discharge was delayed (Group B)

Reason for delay*	**Treated at home hospital (n=31) %**	**Treated at alternative hospital (n=143) %**	**Total (n=174) %**
Waiting for medication	41.9	23.8	27.0
Waiting to see doctor	12.9	21.7	20.1
Waiting for transport	6.5	32.9	28.2
Other/more than one/not told	38.7	21.7	24.7

**Only includes patients who said their departure from hospital was delayed on the day of discharge*

Patients who opted for treatment at RTs tended to be more positive when asked to give an overall rating of the care they had received, reflecting these patients' responses to previous questions (Tables 57 - 60). They were more like to report that they had always been treated with respect and dignity (90%, compared to 83% of home hospital patients) ($p<0.05$), and more likely to rate the care they received as "very good" or "excellent" (88%,

compared to 76% of OT patients) (p<0.001). They were also more likely to say they would definitely recommend the hospital to others (83%, compared to 64%) (p<0.001).

Table 57: Treated with respect and dignity in hospital? (Group B)

	Treated at home hospital (n=186) %	Treated at alternative hospital (n=693) %	Total (n=879) %
Yes, always	83.3	89.9	88.5
Yes, sometimes	16.1	9.4	10.8
No	0.5	0.7	0.7

Table 58: Overall rating of care (Group B)

	Treated at home hospital (n=186) %	Treated at alternative hospital (n=693) %	Total (n=879) %
Excellent	46.2	62.3	58.9
Very good	30.1	26.0	26.8
Good	17.2	8.1	10.0
Fair	5.4	2.5	3.1
Poor	1.1	1.2	1.1

Table 59: Would you recommend this hospital to others? (Group B)

	Treated at home hospital (n=185) %	Treated at alternative hospital (n=694) %	Total (n=879) %
Yes, definitely	63.8	82.7	78.7
Yes, probably	31.9	14.1	17.9
No	4.3	3.2	3.4

Experience also varied according to the type of RT at which the patient had had their operation (Table 60). Patients who had their operations in treatment centres or private hospitals were more positive about their experience than those whose surgery took place at an NHS Trust. Those patients treated at Moorfields St Ann's reported a particularly positive experience, with over 95% of respondents reporting that they were always treated with respect and dignity and that they were definitely happy with their choice of hospital.

Table 60: Rating of care by hospital (Group B)

RT	Excellent	Very good	Good	Fair	Poor
Moorfields St Ann's * (n=94)	75.5	19.1	5.3	0	0
Private hospitals (n=35)	71.4	17.1	11.4	0	0
Ravenscourt Park * (n=72)	63.9	25.0	9.7	1.4	0
UCLH * (n=238)	61.8	27.3	7.6	2.5	0.8
RNOH * (n=68)	58.8	33.8	7.4	0	0
ACAD * (n=97)	58.8	25.8	8.2	5.2	2.1
Other NHS (n=89)	51.7	28.1	10.1	5.6	4.5
Home hospital (186)	46.2	30.1	17.2	5.4	1.1
Total (n=879)	**58.9**	**26.8**	**10.0**	**3.1**	**1.1**

** Treatment centre*

Some interviewees were in a position to compare their treatment at the RT with previous treatment at their home hospital. For the most part these comparisons were unfavourable to the OT:

> *"It's a lovely, modern hospital, very nice, very clean. [NHS Trust] - I've had an experience there with my mother-in-law and it wasn't that clean. The nurses, where I had my operation were wearing caps on their heads. You felt as though you were going into a clean atmosphere. It's the first time I've seen that in a hospital so I was quite impressed by it." (Interview B10: female, aged 58, had varicose veins operation at NHS treatment centre)*

> *"The appointment was very, very rapid at [NHS Treatment Centre] and secondly the method of operation was completely different to the method of operating at [NHS Trust]. I found the one at [NHS Treatment Centre] far better. It didn't leave you with an aftermath of pain or anything like that. The first one, it was pretty ropey for a good week but this one was pretty good. It was far, far more comfortable than the other one." (Interview B12: male, aged 73, had cataract operation at NHS treatment centre)*

> *"It was good. There was an inspection for cleanliness. A matron type woman came round with a management woman and said 'What do you think of the room?' She said 'Is it clean?' and I said 'Yeah' because it was, it was spotless! You couldn't fault that side of it at all. Going back a few years now when [NHS Trust] was going through a bad period and it was filthy wasn't it? There was rolls of dust under the*

beds. It was quite frightening!" (Interview B2: male, aged 59, had hernia operation at NHS treatment centre)

The fact that those treated at alternative hospitals were more positive in their evaluations may reflect better quality of care in the treatment centres or private hospitals where most of them had their operations. It is important to bear in mind that patients involved in the LPC had in many cases moved from NHS trusts which were 'poor' performers, to dedicated modern treatment centres, created to perform elective procedures only, without the pressures involved in providing emergency services. The difference was very apparent to the interviewees:

"I think it was a hospital where … it was like a 9 – 5 hospital. There was no outpatients so they didn't have any emergencies. So it was like a little sausage factory – you come in and you go out and it was so streamlined." (Interview B3: female, aged 69, had hip operation at NHS treatment centre).

"The staff were just…they was helpful. Where I know from working in the hospital, they're not very helpful, you know, where I work. But they were just so different. Whether it's because there's only a few people in there or, you know, they didn't have the workload. The place was just so nice. It was clean. It was like…fresh. It was nice. It wasn't really like a hospital, really. It was like a hotel. It was so nice! "I mean, for anyone to go and stay in a place and get what I got, the treatment I got, would be a godsend really, 'cause they was brilliant. They was there for you, if you needed anything they was there for you! They was really, really good!" (Interview B5: female, aged 35, had gall bladder operation at NHS treatment centre)

8.3 Follow-up care and outcomes

When first introduced to the possibility of travelling to a more distant hospital for treatment, many patients had been concerned about possible disruptions to the continuity of their care. In particular, three quarters of Group A survey respondents had indicated that they would prefer to receive follow-up care close to their home. However, the agreed patient care pathways for the LPC scheme included one post-operative check at the hospital where they had been treated, with free transport provided. The *After Surgery* questionnaire included several questions about follow-up care to determine patients' views on whether this aspect of the scheme had caused them any problems.

Patients treated at alternative hospitals were significantly more likely to have had a post-operation check up (83%, compared to 73% of patients treated at home hospitals) (Table 61, $p<0.01$).

Table 61: Did you have a post operation check up? (Group B)

	Treated at home hospital (n=182) %	Treated at alternative hospital (n=681) %	Total (n=863) %
Yes	72.5	82.5	80.4
No	27.5	17.5	19.6

There were also significant differences between the two groups in who provided their follow-up care. Patients treated at OTs were more likely than those treated at RTs to have seen a GP, district nurse or health visitor for post-operation checks and other follow-up treatment, while patients who opted for an alternative hospital were more likely to receive follow-up care at the RT itself (Table 62, $p<0.001$). Twelve per cent of those who had their operation at an RT returned to their OT for follow-up care.

Table 62: Who did you see for your follow-up treatment? (Group B)

	Treated at home hospital (n=90) %	Treated at alternative hospital (n=292) %	Total (n=382) %
Someone from my home hospital	36.7	12.3	18.1
Some from the alternative hospital	5.6	55.5	43.7
My GP	11.1	7.9	8.6
District nurse/health visitor	26.7	16.1	18.6
Someone else/more than one	20.0	8.2	11.0

**Only includes patients who needed follow-up treatment AND received it.*

There was no significant difference between the two groups in their assessment of whether they had received sufficient follow-up care, with two thirds in each group expressing satisfaction with the amount of care received (Table 63). Both groups were equally likely to respond positively when asked if hospital staff had discussed their likely need for health or social services support on leaving hospital, but more of those treated at RTs (45% compared to 37% of those treated at OTs) said this had not been necessary, suggesting that those who stayed at their home hospital may have had more complex needs than those who opted for an alternative hospital. Most respondents in Group B (77%) said their GP had been given all necessary information about their treatment and there was no significant difference between the groups in this respect.

Table 63: How much follow-up treatment did you get? (Group B)

	Treated at home hospital (n=102) %	Treated at alternative hospital (n=370) %	Total (n=472) %
The right amount	65.7	67.0	66.7
Some, but not enough	25.5	19.2	20.6
I wanted follow-up treatment but did not get any	8.8	13.8	12.7

Only includes patients who felt they needed follow-up treatment.

However, some interviewees expressed concern about the limited amount of after-care they received from the hospital, and several had turned to their GP for advice and reassurance:

> *"The only complaint I have about the treatment was the follow-up treatment. They didn't provide any physiotherapy". (Interview B4, female, aged 57, had knee replacement at NHS treatment centre)*

> *"You weren't given the choice to go back to see a consultant. I came out of hospital and that was the end! I had to take my own dressings off… it's quite scary. I got my daughter to do most of them. I would have liked to have gone back to the doctor and really for the doctor to have taken the dressings off and then do a follow-up after that on how my legs were and everything but I didn't have anything. I'm going back again [to GP] because I just need sort of verification really." (Interview B10: female, aged 58, had varicose veins operation at NHS treatment centre)*

Nevertheless, most interviewees were delighted with the outcome of their operation, describing the tremendous difference it had made to the quality of their lives:

> *"The operation was as good as operations can get! After eleven weeks I could walk without anything, without crutches, without sticks. Before I had such agonising pain in my leg but now the pain's completely gone from my leg. I can cross my legs, I can bend down, I can dry my toes, I can do everything!" (Interview B1: female aged 60, had hip replacement at NHS treatment centre)*

> *"It's the best thing I've had done! I've suffered for so long. After the operation they gave me something to eat and it was unusual to be able to eat something and not have all the pain. It was heaven!" (Interview B5: female aged 35, had gall bladder operation at NHS treatment centre)*

> *"I couldn't see the words on the television and to read I was getting large print books from the library and using a magnifying glass. The consultant, Mr X, said it should*

have been done a lot sooner! It's been an absolute revelation (the operation) to me. You don't realise how much sight you've lost until you get it back!" (Interview B11: female aged 76, had cataract operation at NHS treatment centre)

For the most part, concerns about disruptions in continuity of care for those treated at RTs turned out to be unfounded. The LPC team had placed considerable emphasis on developing agreed patient care pathways for each procedure and this effort appears to have paid off, at least as far as the patients were concerned, since both groups were equally satisfied with their follow-up care.

9 Patients' assessment of London Patient Choice

As we have seen, levels of satisfaction with the offer of choice, the support given by PCAs, the care they received in the RTs, and with follow-up arrangements were high among those patients who had opted to go to an alternative hospital. And in most cases patients who had opted to have their treatment in an RT reported significantly better experiences than those who remained at their home hospitals.

The majority of survey respondents (85%) were happy with their choice of hospital and there was no significant difference in this respect between those treated at home hospitals and those treated elsewhere. When the sample was analysed by sub-groups, comparing sex, age-group, social class, employment status and health status, there was little difference in the proportion who were satisfied, with a substantial majority in each sub-group saying they were definitely happy with their choice (Table 64).

Table 64: Proportion satisfied with choice of hospital (Group B)

		Treated at home hospital (n=177)		**Treated at alternative hospital (n=662)**	
		% who said "definitely happy"	Significance	% who said "definitely happy"	Significance
Sex	Male	85.9		86.8	
	Female	74.7	n.s.	87.5	n.s.
Age group	Under 60	71.0		84.5	
	60 and over	86.1	p<0.05	89.2	n.s.
Social class	Class 1,2	76.4		83.8	
	Class 3,4,5	81.5	n.s.	90.4	n.s.
Employment status	Employed	69.2		84.4	
	Not employed	83.8	n.s.	88.3	n.s
Health status	Good	80.0		89.7	
	Poor	66.7	n.s.	77.4	p<0.001

The only significant differences were as follows: among those treated at OTs, younger people tended to be slightly less satisfied than older people ($p<0.05$), while among those treated at RTs, people who rated their health as poor were less satisfied than those who rated it as good ($p<0.001$), but they in turn were more satisfied than those in poor health treated at their home hospitals.

Patients who had chosen to go to an alternative hospital were significantly more likely to recommend the LPC scheme to others (97% compared to 73% of home hospital patients, $p<0.001$, Table 65). Not surprisingly, a significant proportion (21%) of those who opted to stay at their home hospital felt they could not comment on the initiative.

Table 65: Recommend London Patient Choice scheme to others? (Group B)

	Treated at home hospital (n=175) %	**Treated at alternative hospital (n=662)** %	**Total (n=837)** %
Yes, definitely	43.4	87.2	78.0
Yes, probably	31.4	10.6	14.9
No	4.0	1.2	1.8
Can't say	21.1	1.1	5.3

This positive assessment was echoed by interviewees. They highlighted various advantages of the scheme, in particular the reduced waiting time:

> *"Yes I would absolutely recommend it to anybody, because in my case, and I'm hoping it's the same for everybody else, it was the best thing that could have happened because I ended up with a leg that I could walk on six months earlier than what I would have if I'd had to wait at [Trust II]. I actually got to go to the hospital that I would have loved to have gone to but thought I didn't have a chance of going. So the way it all turned out for me was the best thing that could happen." (Interview B1: female, aged 60, had hip operation at NHS treatment centre)*

> *"Yeah, it's a good idea, it's a must really isn't it? You know, especially if you're suffering and you're in pain, rather than wait for one particular place, if you get the choice of another place. I mean certainly when you're in pain you don't care, you've got to have it done wherever they send you if you can get it done quicker." (Interview B9: male, aged 63, had hip operation at alternative NHS trust)*

> *"The choice is there. You either sit and wait or you take the opportunity and go. It's just one of those things, I didn't want to sit around waiting for months on end. My*

first eye they told me it was going to be in six months, and in six months it was going be eight months, and in eight months it turned into over a year. But with this they contacted me and we said yes, and within a couple of weeks you'd got date and admission and the operation and everything. So it's a good thing, as long as it's not abused." (Interview B12: male, aged 73, had cataract operation at NHS treatment centre)

Others saw the scheme as a means of tackling previously intractable problems in the NHS. They felt it had helped to address failings in the system:

"I think it's a good scheme because the general hospitals like [Trust IV] are over-powered by what they've got to deal with. In [London suburb] we've only got one hospital and the population is tremendous." (Interview B6: female, aged 68, had hip replacement at NHS treatment centre)

"It's like the choice I had where I had my legs scanned privately. I hate doing things like that private because I think you pay for the NHS system to be in place to serve your needs. I know the needs are now far greater than what they were years ago because we've got more people in the country and I hate to think that I'm jumping the queue and someone else is waiting more months to go and have something done. I think it should be a fair system right round, that, within reason, you shouldn't have to wait months and months and months and months. But as I say this sort of system might make things a lot easier for the hospitals and everybody will be happy all round". (Interview B10: female, aged 58, had varicose veins operation at NHS treatment centre)

On the basis of this feedback from patients, it is reasonable to conclude that the LPC scheme is meeting its objectives in terms of providing faster access to good quality care, which is for the most part well-coordinated and responsive. The degree of support provided by the PCAs, the provision of free transport and the development of agreed care pathways has ensured that the transition between different hospitals is relatively unproblematic for patients. Indeed, in many respects those patients who received treatment at one of the RTs reported significantly better standards of care than those who opted to stay at their home hospital, with the added bonus of reduced waiting times.

There are some problems, however, that require attention. The most serious of these is the failure to provide sufficient information to enable truly informed choices. A significant proportion of survey respondents – one in three – was critical of the amount of information they had received, particularly in relation to the lack of information about the quality of care offered by the different hospitals. The advice and support provided by PCAs was greatly appreciated, but it seems they were frequently unable to provide detailed information of the type required by many patients, some of whom felt unprepared for the decision they were being asked to make.

The provision of free transport is a popular aspect of the scheme and undoubtedly contributes to the high uptake of treatment at RTs amongst those offered a choice, but the arrangements do not always run smoothly. Late arrival of transport caused delays in discharge for nearly a third of patients treated at RTs and in some cases the type of transport provided appeared inappropriate to patients' needs.

And finally, the reason why two-thirds of apparently eligible patients were not offered a choice requires further investigation. When news about the success of the scheme from the patients' perspective becomes more widely known, public demand for choice is likely to grow. Dissatisfaction with the NHS may increase if this opportunity continues to be denied to a significant proportion of Londoners without good reason.

10 Implications for the national choice programme

We have seen that the hospital choice model developed and implemented in London succeeded in providing faster access to good quality care and was popular with patients. But the new choice-at-the-point-of-referral scheme that is planned for national roll-out from December 2005 differs in several important respects from London Patient Choice. Patients will be expected to make a choice much earlier in the process of care, often before they know whether specialist treatment or a hospital admission will be required. Here we consider the implications of our findings for the new national scheme.

10.1 Demand for choice

It is rare for patients to be referred directly for admission to hospital, except in emergency situations. Instead the first referral is usually to a specialist outpatient clinic. There are a variety of reasons for referring patients to outpatient clinics, including referral for diagnosis or for an investigation which cannot be done by the GP, referral for advice on the best means of treating the patient's condition, referral for the specialist to initiate a course of treatment, referral for a second opinion or to reassure the patient.[19] The factors patients consider important when being referred for advice or diagnosis may differ significantly from those they take into account when expecting to be admitted to hospital for surgery. For example, ease of travel and proximity to home are likely to feature more strongly if a patient suspects that they will have to undergo a series of outpatient consultations. So the high rate of acceptance of an alternative hospital seen in London Patient Choice and in CHD Choice may not be replicated in the national scheme.

There are other reasons for thinking that rates of uptake may differ and may vary across the country. In large population centres such as London it is realistic to assume that a range of alternative locations will be reasonably accessible, but this assumption may not be so realistic in more rural areas. The provision of free transport for all is very unlikely to be replicated across the country because it will be considered unaffordable, so transport will be provided only for those who can demonstrate a need. Since this was a key factor in promoting high rates of uptake in London Patient Choice, we might expect interest to diminish if this is not so readily available. Also, if the government succeeds in continuing to drive down waiting times, both for outpatient appointments and inpatient admissions, the motivation of faster access to services may lose its force.

However, we have seen that fast access and free transport were not the only considerations that influenced patients' decisions. Many patients were aware that the quality of care varies from hospital to hospital and even between departments within hospitals. Furthermore, some patients wanted to be treated by particular individual

19 Coulter A. The interface between primary and secondary care. Chapter 1 in Roland M, Coulter A (eds) *Hospital Referrals.* Oxford: Oxford University Press, 1992

surgeons and were willing to travel to secure this. Most people would prefer to see high quality standards in every NHS facility, but the recent policy emphasis on raising quality standards has drawn public attention to the fact that standards are uneven. It seems quite possible that as more data on quality of care and outcomes in different facilities becomes publicly available and the public learns to be more discriminating about these issues, the desire for a choice of provider will grow. So the reasons for wanting a choice of referral location may change in subtle and perhaps unpredictable ways.

We saw that expressed willingness to consider going to an alternative hospital was only partially accurate as a predictor of what people did when faced with a real choice. About a third of our survey respondents changed their minds when they had to make a decision. This evidence of volatility, coupled with the value they placed on hard-to-measure concepts such as *reputation,* suggests that their choices could be influenced by effective marketing. When *Payment by Results* is fully implemented and hospitals have a financial incentive to attract patients and a strong disincentive to lose them (in contrast to the protected funding provided to trusts in London Patient Choice scheme), we may see an intensification of efforts to promote individual hospitals by *branding,* as in retail markets. Intensive marketing strategies could significantly influence the demand for choice.

10.2 Impact on quality standards

In theory the choice system should give providers a strong incentive to increase throughput and drive up quality standards, but this will only happen if patients behave like discriminating consumers. Our study results have demonstrated that the offer of a choice of treatment location is popular and patients can and do make choices, often weighing up a complex combination of factors to arrive at the decision that feels best for them. However, we also observed a gap between the information patients felt was necessary to make a truly informed decision and what they actually received. Insufficient effort appears to have been made by the trusts, by Strategic Health Authorities or by the Department of Health to fill this gap. Some individual trusts provided leaflets about their services but the content was of varying degrees of usefulness. It was very difficult for a patient wanting to compare the quality or safety record of alternative hospitals, for example, to obtain adequate information in a standard format to enable this. Certainly the star ratings are much too crude to meet this need.

Before being offered a choice many patients expressed a desire to talk over the options with their GP. In the event very few did this, relying instead on the limited information and advice provided by the PCA. When these decisions have to be made at the point of referral, it should be more possible for patients to seek their GP's advice and it is likely that many will do so. There is a risk though of a return to something closer to the current system whereby GPs make the decision about where to refer, often with little explicit consultation with the patient. This might be acceptable if we could assume that a) the GP has access to reliable information about the quality of care in each specialty department in the different locations, b) the GP has sufficient knowledge of the patient's situation and preferences to make 'the best' decision for them, and c) the patient is willing to delegate decision-making to the GP and has no desire for a more active role. The evidence suggests that these would be unwise assumptions in many cases.[20,21]

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20 Coulter A. The patient's perspective. Chapter 9 in Roland M, Coulter A (eds). *Hospital Referrals.* Oxford: Oxford University Press, 1992

21 Coulter A. *The Autonomous Patient.* London: Nuffield Trust, 2002

Many patients seek help with making a choice simply because the issues are so complex, so they tend to rely on the advice of others, such as their GP. GPs will require access to reliable, unbiased information about quality standards among different providers if they are to advise their patients, but patients in our study also wanted access to independent information sources. If policy-makers are serious about the intention to use this type of scheme to drive up quality standards, they must support it with better and more accessible performance information than has been available hitherto.

Having to compete for patients may make hospital staff more responsive, but we cannot assume that this explains the better performance of RTs against OTs in our study. It is more likely to be attributable to the fact that the treatment centres, dedicated units and private hospitals where many opted to undergo surgery offered more favourable conditions in which to respond to patients' needs than the often hard-pressed OTs that were exporting patients. However, the differences do demonstrate that higher standards for NHS patients are achievable and that treating elective surgery patients separately from those needing emergency services has much to commend it.

The results also demonstrate that it is possible to manage a system-wide approach to capacity use without adverse consequences for patients, if sufficient attention is given to developing organisational relationships and patient care pathways. In recent years a great deal of attention has been devoted to finding better ways of using existing resources in the NHS and London Patient Choice is only one of many examples. Indeed, some hospital managers might argue that increasing choice for patients was not really the point. The scheme was attractive to them because it offered a means of challenging existing working practices that were perceived to be inefficient, i.e. a means to an end rather than an end in itself. Certainly the scheme represents a challenge to hospital consultants who lose direct control of their waiting lists, with potentially profound consequences for their role. This need not necessarily worry patients unless it results in a reduction in continuity of care or an erosion of the doctor-patient relationship, as some have predicted. We found no evidence that this was occurring and indeed the concerns may be overblown, in the light of the fact that most of the LPC patients were undergoing relatively straightforward procedures often carried out on a day case basis with little need for ongoing treatment. However, this could become a more serious issue when the *Choose and Book* scheme is implemented across the country. Particular attention should be paid to ensuring coordination across service boundaries, for example in shared care regimes and links with social services.

10.3 Impact on equity of access

Despite initial concerns that more advantaged patients would benefit from the choice scheme to a greater degree than those in the less advantaged groups, we found no evidence of inequalities in access to, or uptake of alternative hospitals by social class, educational attainment, income or ethnic group. The only factor that had a significant impact on the likelihood of accepting the offer was employment status – not surprisingly, people in paid employment were even more keen than those who were unemployed or retired to have their operation as quickly as possible.

However, these encouraging results were achieved as a result of removing the usual barriers to access, in particular by providing support to patients who needed help to

navigate their way through the system (the PCA's role) and by providing free transport for all. It is not yet clear what level of support will be available to patients making choices at the point of referral, but unless some support is available there is a risk that inequalities in uptake will start to emerge. Patients will need information, advice and sufficient time to absorb this and make decisions. It is virtually certain that transport will not be arranged for everybody in future and instead some type of entitlement criteria will be developed to identify those who need it most. This system will need to be carefully monitored to ensure that it does not discriminate against particular groups and that the transport provided is well organised and appropriate for patients' needs.

While the offer of choice was not obviously associated with any of the socio-economic indicators measured in our study, the likelihood that a patient would be offered a choice did vary according to where they happened to live and which waiting list they were on. Some OTs submitted the names of a far greater proportion of their patients to the London Patient Choice scheme than others. Indeed, overall the proportion of eligible patients who were offered a choice was surprisingly low, at only one in three. The reasons for this are not entirely clear. It is possible that waiting times in the relevant specialties decreased rapidly after the scheme was launched, but it is also possible that staff in OTs developed ways and means to ensure that their patients were not offered the opportunity to go elsewhere. Consultants at participating OTs may have faced conflicting incentives. On the one hand there was an incentive to reduce waiting times so as to meet the government's targets, with attendant benefits for the trust's star rating. On the other, they faced the dispersal of a proportion of their patients with possible knock-on effects for teaching, research and private practice.

The new choice-at-the-point-of-referral scheme will remove some of the disincentives and acute trusts' potential for gaming the system, but the burden will now fall on GPs and their staff. They are likely to be very sensitive to any additions to their workload and will also be well placed to block or delay the choice system. If all patients are to have an equal opportunity to make choices, their right to do so must be clearly explained and monitoring systems must be put in place to ensure that patients get what they are entitled to. Whatever happens, the availability of choices is likely to be constrained in some areas and in some specialties, so geographical inequities may continue to be a feature of the scheme.

Currently there are also inequalities between different patient groups in the opportunity to make choices. The London Patient Choice scheme was restricted to patients awaiting elective surgery. Choice-at-the-point-of-referral offers the potential to reach a much wider population of patients, but it is not yet clear whether the scheme will have much to offer those requiring emergency care or long-term care. The government's White Paper on choice took a broad view of choice and promised greater opportunities for patients to influence their care in a number of different scenarios, going way beyond the relatively simple option of choosing where to be treated and including emergency and long-term care.[22] But the Choose and Book scheme has been designed for elective referrals and it is hard to see how it could be adapted to meet the needs of these other groups of patients.

22 Secretary of State for Health. Building on the best: choice, responsiveness and equity in the NHS. London: HMSO, 2003

10.4 Conclusion

Rates of uptake in this study were high, but they do not provide a reliable guide to the likely demand for alternative providers when the national scheme is rolled out. The new *Choose and Book* scheme will be different from the model piloted in London in several important respects. Acceptance of the offer of non-standard referral options is likely to be affected by various factors, including reasons for referral, prevailing waiting times, travel arrangements, public awareness of quality standards at the different facilities, and perceptions of the reputation of different providers.

Market incentives will only help to drive up quality standards if patients are able to act as discerning consumers, so they and their GPs will require reliable unbiased information about quality standards in different provider facilities. Dedicated elective surgery centres, agreed patient care pathways and coordination across service boundaries are other key elements which can help ensure a high quality service for patients undergoing elective procedures.

If all patients throughout the country are to have an equal opportunity to make choices about where and when they are referred, they must be made aware of their rights in this regard, support and information must be readily available, and monitoring systems must be implemented to avoid the risk of discrimination against less advantaged groups.

Appendix

1 Questionnaire development

The first task was to develop and test the questionnaires using qualitative methods. The in-depth interviews carried out during this stage also generated data on patients' perceptions of choice and the factors influencing their decisions (see 2 below).

- The aims of the development work were:
- To identify issues important to patients who may be offered a choice of hospital;
- To test the feasibility of using a postal questionnaire to engage patients in a discrete choice experiment to investigate their preferences for alternative health care providers;
- To test the draft questionnaires for comprehensibility and face validity.

In-depth interviews were carried out to inform the development of the questionnaires *as well as* to learn more about the factors likely to influence patients' reactions to being offered a choice of hospital. Draft questionnaires were then tested in 'cognitive' interviews to check the comprehensibility and relevance of the questions. The questionnaires were revised where necessary and then re-tested. The final version of the questionnaire was then sent to the multi-centre research ethics committee to seek their approval of the changes. This was granted on the 20th August 2003.

Development of *Before Surgery* questionnaire

The initial draft of the Before Surgery questionnaire drew on the following sources:

- A review of the literature carried out by Picker Institute researchers during their evaluation of the CHD Choice scheme;
- A review of studies relevant to the discrete choice experiment carried out by Peter Burge of Rand Europe;
- Focus groups and interviews carried out by staff of the Picker Institute in the initial stages of the evaluation of the CHD Choice scheme;
- The questionnaire used in the CHD Choice evaluation;

- The Picker adult inpatient questionnaire which is used in the national NHS patient survey programme.

Interviewees were asked to complete the draft questionnaire in front of the interviewer and to talk about the thought processes they used to come up with their answers. They were asked specific questions to probe their understanding of the concepts and terminology in each item. Once they had completed the questionnaire they were asked to recommend ways in which the questionnaire might be improved to make it more user-friendly.

Specific feedback was requested about the discrete choice experiment which comprises three pages in the twelve-page questionnaire (pp.6-8) to find out if it was comprehensible and easy to complete.
Respondents were asked:

- If they had had any difficulties in completing this section;
- If they understood the choices they were being asked to consider;
- Whether any of the factors listed were not important in making their choice;
- Whether there were any other important characteristics of hospitals that might be a factor in making a choice.

Following this procedure the questionnaire was amended and tested again. Twelve patients who had participated in the interviews were contacted by telephone to ask if they would complete the revised questionnaire and feed back their responses via a brief telephone interview. Ten of these completed the task. No further problems were identified.

The following topics were included in the final version of the questionnaire:

- Name of procedure awaited;
- Length of wait and information about admission date;
- Travel arrangements to home hospital;
- Views on home hospital's reputation;
- Attitudes to choice of hospital;
- Information and advice requirements;
- Relative importance of factors influencing decision;
- The discrete choice exercise;
- Current health state, including the EuroQol (EQ-5D) instrument (www.euroqol.org);

- Sex, age, educational status, carer status, employment status, household income and ethnic origin.

Development of *After Surgery* questionnaire

The *After Surgery* questionnaire was an adaptation of the questionnaire used in the CHD Choice study. It was expanded to incorporate new questions derived from the in-depth interviews and from organisational case studies carried out by the team of researchers at Royal Holloway and Imperial College.

The questions about information sources, satisfaction with information received and follow-up care were expanded, and a detailed set of validated questions drawn from the Picker adult inpatient questionnaire was added. This questionnaire also includes a set of questions about employment status and occupation to enable derivation of respondents' social class.

The draft questionnaire was further tested in cognitive interviews with five patients who had been through the LPC scheme.

2 Interview procedure

Before Surgery interviews

Trust IV was identified as a suitable base for recruiting patients for the initial interviews. Permission to conduct the research was granted by the Chief Executive of the Trust.

In the LPC, patients eligible to be offered choice are telephoned by a PCA when they have been on a waiting list for approximately four and a half months to explain the scheme and invite them to take part. It was important for the purposes of the study to gain the views of patients prior to this contact. We therefore contacted patients who had been on the waiting list at Trust IV for between one and three months. The sample, which was drawn from orthopaedic and general surgery waiting lists, was purposive and sought to include patients of both sexes and a range of ages, waiting for a mix of 'choice' procedures, e.g. day case and inpatient.

Patients were sent an information sheet describing the study and a letter inviting them to take part in an interview. Those who agreed were asked to sign a consent form prior to being interviewed. The letter emphasised that taking part in the study would not increase the likelihood of being offered a choice and refusal to participate would not affect future care in any way.

The invitation was sent in April 2003 to 94 patients. A freephone number was provided for patients to call if they had any queries or wanted to opt out of the study. Invitation letters were followed up after seven days by a telephone contact to ask if they would like to participate. If they were not contactable, an answerphone message was left with a request to call the freephone number. Patients who did not have an answerphone were called again up to a maximum of two times. In a few cases, the telephone number provided by the patient's home hospital was incorrect. These patients were sent a further letter with a request to call the freephone.

This procedure resulted in 27 completed interviews. Twenty-five of these were conducted in patients' homes, one took place at the interviewee's workplace, and one opted for a telephone interview as she was too busy to be interviewed at home. When family members or carers were present their views were also sought. The interviews were conducted by two researchers from the Picker Institute: 25 by LH and 2 by NLM.

The sample consisted of slightly more women (16) than men and most interviewees were of white British origin; most owned (13) or had access to a car (8) and were in employment (11). Eight interviewees were retired and four were unable to work because of disability or ill health. Most lived in two-person households (10); six had children still at home and five lived alone. Most orthopaedic patients were waiting for hip (5) or knee replacements (4) and most general surgery patients were waiting for a varicose veins operations (8) or hernia repair (6).

There were two parts to the interview. One part was designed to explore patients' attitudes to being offered a choice of hospital and the factors likely to influence their decision. A semi-structured interview schedule was developed, with plenty of open-ended questions to stimulate discussion. The second part focused on testing patients' comprehension of the questionnaire, using cognitive techniques to check meanings and understanding of concepts and probe questions to identify any important issues that had been omitted from the draft. The order in which respondents were asked to participate in these two tasks was varied so that some patients completed the questionnaire before the in-depth interview and others did it afterwards.

At the end of the interview, the researcher summarised her understanding of the interviewee's views and asked for comments. This gave interviewees an opportunity to correct or clarify any issues.
The main topics covered were:

- Views of interviewees about their 'home' hospital, i.e. where they were currently expecting to be treated
- Their views on choice
- Whether they would accept the option of quicker treatment at an alternative hospital if it was offered
- Who they would wish to discuss their options with
- The type of information they would seek and where they would look for it
- Their views on travelling for treatment, including transport arrangements and how far they would be prepared to travel
- Whether there were any other factors they considered important that might affect their decision about whether or not to consider alternative treatment locations

Twenty-five interviews were recorded and transcribed. One patient did not wish the interview to be tape-recorded, so notes were taken by the researcher and used with the

permission of the respondent. Notes were also taken during the telephone interview with the patient's permission. The typical interview length was about one hour.

The transcripts were checked for accuracy by listening to the tapes. Each transcript was read by one researcher (LH). Key themes were identified and a list of categories drawn up. Extraction of themes from the interview transcripts ceased when it became apparent that no new categories were emerging, i.e. data saturation.

Following this broad 'open coding', individual responses to each of the questions were allocated a code. These were quantified and compared across categories and in relation to independent variables: sex, age and type of procedure. Relevant issues that arose while discussing the questionnaire were included in the analysis.

After surgery interviews

A request slip inviting patients to take part in an interview was enclosed with the *After Surgery* questionnaire. Patients were asked to complete the request slip with their contact details and return it along with the questionnaire if they were willing to participate. A freephone number was provided to enable patients to contact the researchers directly.

The sample was selected to include a broad age-range and a balance between those who had opted to go to an alternative hospital and those who had decided to remain at their home hospital. Patients' who agreed to participate were sent an information sheet describing the study and interviewees were asked to sign a consent form prior to being interviewed.

This procedure resulted in 24 completed interviews: 13 with patients who were treated at an alternative hospital and 11 with patients who declined the offer of an alternative. In addition five relatives or carers were interviewed. 17 interviews took place in patients' homes, three in patients' work places and one in a hospital setting. Three patients opted for telephone interviews as they were too busy to be interviewed at home. The interviews took place during March and June 2004 and were conducted by two researchers from the Picker Institute: 12 by LH and 12 by NLM.

A semi-structured interview schedule was developed, with plenty of open questions to stimulate discussion.

The main topics covered in the interview with patients treated at their home hospital were as follows:

- Views on the information provided about the LPC scheme
- Views on the PCA service
- Their experience of the inpatient stay
- Their experience of after-care
- Their reasons for deciding to remain at their home hospital

The main topics covered in the interviews with patients treated at an alternative hospital were:

- Views on the information provided about the LPC scheme
- Views on the PCA service
- Their experience of the process of choice, including travel and accommodation arrangements
- Their experience of the inpatient stay
- Visiting arrangements: was it convenient for friends and family?
- Their experience of after-care
- Views about the LPC scheme
- Carers' views of the scheme

Twenty-four patient interviews were recorded and transcribed. The typical interview length was about one hour. Each transcript was read by one researcher (LH) and transcripts were checked for accuracy by listening to the tapes. Key themes were identified and a list of categories drawn up. Following this broad "open coding", individual responses to each of the questions were allocated a code. These were compared across categories and in relation to independent variables: sex, age and type of procedure.

Interviewees included 12 male patients and 12 female patients; 14 were in the 60 to 79 age-group, 8 were aged between 45 and 59 and 2 were under 45; 6 had hip replacements, 5 had knee replacements, 6 had hernia repairs, 3 had varicose vein operations, 2 had cataract operations, 1 had a cholecystectomy and 1 had a prostatectomy.

3 Record review

In July 2004 data from the LPC administrative records were examined to determine the decisions made by patients following the offer of treatment at alternative hospitals. Records were searched for all patients sent the *Before Surgery* questionnaire. Outcomes were categorised as follows:

1. Offered a choice – opted to be treated at home hospital
2. Offered a choice – opted to be treated at alternative hospital
3. Offered a choice – other outcome (e.g. operation cancelled, patient moved away)

4. Not offered a choice – patients whose name did not appear in the LPC administrative records, either because they were deemed ineligible or because they had not reached the appropriate point on the waiting list.

Data obtained from the record review was cross-tabulated against demographic data obtained from respondents to the *Before Surgery* survey.

4 Recruitment of participating trusts

In April 2003, staff of the LPC coordinating team approached Chief Executives of a number of suitable Originating Trusts with an invitation to participate in the study. Provisional agreement was obtained from the chief executives of five of these Trusts. The study design had been peer-reviewed and approval had been obtained from the Multi-Centre Research Ethics committee, but it was also necessary to obtain approval from additional individuals and committees in each trust, including data protection officers and Caldicott guardians, research and development directorates and information staff responsible for drawing the sample.

The process of obtaining agreement from all relevant parties took considerably longer than anticipated, spanning a period of eight months in the case of three of the Trusts. A further Trust invited to participate eventually agreed to do so in January 2004, but this decision came too late to include patients from this trust. As a result of these recruitment problems the initial sample size was lower than originally anticipated and it was therefore decided to recruit an additional sample of patients who had gone through the LPC process prior to December 2003 (group B).

5 Recruitment of patients

***Before Surgery* survey**

Recruitment of patients from the five participating OTs commenced on 18th September 2003 when the first of the five trusts supplied the necessary patient data. The researchers at the Picker Institute were given honorary contracts by the participating OTs to enable them to send out the questionnaires directly to patients. Mailing to consecutive batches of patients was carried out prospectively as patients became eligible to receive the questionnaire (i.e. as soon as they had been on the waiting list for one month) and recruitment continued until 16th January 2004. Following an initial mailing, non-

responders were sent up to two further reminders at two-week intervals. The final reminders to non-responders to the *Before Surgery* survey were mailed on 13th February 2004.

After Surgery survey

Mailing of the After Surgery questionnaire began on 20th February 2004 and continued until 28th April 2004. The final reminders to non-responders were mailed on 26th May 2004.

The patient's pathway through the system - from one month after joining the waiting list to six weeks after surgery - takes a minimum of six and a half months, and considerably longer for those remaining at their 'home' hospital. In the original study protocol the intention was to send the *After Surgery* questionnaire to all those who had returned a *Before Surgery* questionnaire. However, delays occurred in the mailing process because trust staff took much longer than originally anticipated to release patients' names and addresses. As a result of these delays, the number of patients becoming eligible to receive the *After Surgery* questionnaire within the timeframe of the project was much lower than anticipated. The issue was resolved by recruiting an additional sample of patients who had been through the LPC choice process before the study commenced (i.e. those who received their treatment between 1st June 2003 and 30th November 2003). Permission to draw this additional sample was granted by a contact at each of the OTs.

In addition to the 218 *Before Surgery* survey respondents who had reached the point where they were eligible to receive the *After Surgery* questionnaire, a new sample of 1621 patients was recruited for the second stage of the study.

Picker Institute Europe
King's Mead House
Oxpens Road
Oxford OX1 1RX

Tel: +44 (0)1865 208100
Fax: +44 (0)1865 208101
Email: info@pickereurope.ac.uk
Website: www.pickereurope.org

Charity Registration no: 1081688

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