

TAKING SOUNDINGS
Patient and Public
Involvement in the London
Patient Choice Project
Testing the views of patients
including 'hard to reach'
groups

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Strengthening Public Influence in Health

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The Interfaith Network
The Mayor's Children and Young Peoples Unit (GLA)
The British Council for Disability
Groundswell UK
Age Concern London

List of participating organisations:

Action for Sick Children
Alzheimer's Society (Enfield, and Hammersmith & Fulham Branches)
ATD Fourth World
Brent Multi-Faith Forum
Contact a Family
Counsel and Care
Heston House Elders Care Home
Greenwich Association of Disabled People
Katherine Low Settlement Pensioners' Club
Mencap
MIND – Southwark MIND
Thames Reach Bondway
UK Youth Parliament

EXECUTIVE SUMMARY

Context: Patient Choice is the policy where individual patient involvement and collective public involvement intersect: patients will choose where to go for their own treatment and also pressurise hospitals to improve by collectively abandoning those which do not meet their standards. However, Choice inequalities may reinforce existing health inequalities by empowering some patients but disempowering others even further. Choice is a challenge for the NHS but it must not also be a challenge for patients.

Excluded to start with: Almost two thirds of patients admitted to hospital are over 65, and some are very frail and dependent with multiple health problems. People living in poverty are more likely to suffer conditions needing hospital care, as are certain ethnic minority groups. Such personal disadvantage may be exacerbated by information disadvantage including language difficulties, lack of Basic Skills or total unfamiliarity with the internet. These barriers to choice require the right information and support to be free and accessible. *Taking Soundings* was a patient and public involvement exercise intended to find out how this might be done.

Building on work with its Patient Reference Group, Health Link approached over 50 organisations working with 'hard to reach' groups. 13 organisations facilitated our involvement with carers, older people, disabled people, families with sick and disabled children, faith communities, ethnic minority groups, mental health service users, care home residents, young people, homeless people and those living in poverty. Almost 90 people considered the issues through the framework of the *Taking Soundings* survey form in a range of involvement methods including face to face or telephone semi-structured interviews and self administered survey forms. Separate work has been commissioned from the Black Londoners Forum to get a more thorough perspective on black and ethnic minority groups, which will be published as a supplement to this Report.

While participants in the *Taking Soundings* were generally enthusiastic about Patient Choice, particularly choice of appointment date and time, many were sceptical about whether the NHS could deliver it.

Choosing where to be Treated: Information participants wanted to help them choose between hospitals is set out in full in the Report, and fell into four categories:

Access - ranging from how to get to the hospital, to waiting times for the procedure
Quality - covering performance such as mortality rates and cancelled operations as well as

- Environment (ranging from disabled access, to availability of Prayer Rooms)
- Staff (ranging from levels of agency nurses, to skills in dementia)
- Processes (ranging from numbers of visitors allowed, to communication with GPs)

Policy - ranging from carer involvement, to parents allowed in the Recovery rooms

Subjective and attitude - ranging from quality of nursing care, to respect and dignity.

Participants required authoritative information which could be accessed through a range of media (written, telephone support and internet based) to meet diverse needs and so that they could cross check information if they were unsure. Written information must be in audio and Braille as well as languages other than English and formats suitable for children and those with a learning disability. Personal support was raised repeatedly as essential in accessing and understanding the information and worries were expressed about GPs being appropriate for such a role, although most saw their GP as last resort in case of doubt.

Choosing when to be Treated: The proposed process of booking appointment date and time, was seen as accessible. Enough time must be built in for patients to reflect on information before having to book. Patients would also need time to sort out practicalities such as childcare. Careful implementation is essential to avoid adding stress to lives already stressed by illness or personal disadvantage. The practicality of GP involvement in the booking process was questioned, with worries that patients would feel pressured knowing there was a waiting room of patients being held up while they went through the booking process. The password was seen as discriminatory, impractical, stressful, and a barrier to the benefits of Choice.

There were mixed views about the accessibility of the Telephone Call Centre, with requirements for clear information on the system as well as support and help for those who felt excluded by it. Experience of other telephone services with menus and recorded messages did not inspire confidence. Some older people whose first language is not English, would not use the telephone unless it was guaranteed to be answered in their own language. There were worries that needing someone else to make the call for the patient would increase their dependence even further.

Conclusions and Recommendations: Choice must be part of the drive to improve quality in the whole NHS. It must redress disadvantage rather than aggravate it. Whilst the convenience of 21st century access to services, such as booking a holiday over the internet, is very welcome in the NHS, going on holiday is not the same as being ill. The Choose and Book process may exclude those who need treatment most often.

Choosing where to be Treated

- 1. Quality Dynamic:** Choice must be introduced in parallel with a continuing drive to raise quality throughout the NHS. There is a risk of raising expectations through Choice which can never be met without a system to convert them into reality. A Quality Dynamic is required where PCTs involve patients in commissioning so that their quality concerns can be commissioned and monitored.
- 2. Limits on information:** There is a limit to the value of information in helping people judge quality of a hospital. Additional options such as personal testimony from ex-patients, visits and a 'Visitors Book' need to be explored.
- 3. Information Template:** Although information requirements are diverse, there is likely to be a core of information relevant to most patients and further

information needed by some with particular needs. A Template of information to be provided as core with further topics, to which patients can be signposted, should be developed.

4. **Available information:** Not all information specified is readily available. The template needs to be checked against the National Patient Survey and existing data sets scanned to cover any remaining gaps in information.
5. **Using existing resources for support:** Modes of access to information, such as telephone, internet and personal support, all have drawbacks for certain groups. Telephone services must be free of charge to the caller. UK On-Line Centres should all be briefed about Choice so they can support patients using the internet. Other existing sources of support to disadvantaged people, such as peer support groups and NHS staff themselves, need to be fully briefed before Choice starts, to support patients.
6. **National consistency:** Information needs are diverse but not so diverse that each PCT should work on this alone. To ensure national consistency, the Information template referred to above should be tested the Consumers Association criteria, then converted into written information, Call scripts and web pages, as a starting point for local commissioning. All media must meet best practice accessibility standards with road testing with users as the final arbiter. Developing a Learn Direct package on Choose and Book, to assist those with Basic skills needs, should be explored.
7. **Choice Information 'Brand':** There is much information of variable quality and participants were sceptical about the authoritativeness of information generally. The possibility of a 'brand' in Choice information which is reliable and concise should be explored.

Choosing when to be Treated

1. **Raising awareness:** Those who currently support patients must be ready to support them in booking appointments. Awareness of the process needs to be raised among the statutory and voluntary sector staff before December 2005.
2. **Good Practice outside the NHS:** Experience of Call Centres has not always been positive. Good practice from the commercial and voluntary sector must be incorporated into quality standards and the system road tested with patients.
3. **Password Holder:** The proposed password is a significant barrier for some vulnerable groups. Patients should be able to nominate a password holder to book on their behalf.
4. **Designated E-Booking role:** Assistive technologies, such as textphones, exist but are not widespread. The 'E-Booking' role must be assigned to NHS staff locally, such as GP receptionists, so that this can be done for those who cannot do it themselves.

1. INTRODUCTION

1.1 Context: The London Patient Choice Project Board (LPCP) was a national pilot offering patients a choice of hospital once they had been on the Waiting List for six months. From October 2001 it had a patient representative on the board and a patient involvement process. Health Link was commissioned to carry out further patient and public Involvement work to assist with the development of London Choice at referral. The focus of this project is patient and public involvement in the mechanics of choice in secondary care from the patients' point of view, not the broader philosophy of Choice set out in *Building on the Best*.ⁱ From December 2005, patients are to be offered up to five choices of provider when they are diagnosed by their GP as needing a specialist opinion or hospital treatment. There are two early pilots of this Choose and Book process in London.

1.2 Drivers for Patient and Public Involvement: The following drivers for patient involvement in Patients' Choice in London were recognised by the Project:

- **Duty to consult and involve:** The new duty on NHS bodiesⁱⁱ, including strategic health authorities, to consult and involve patients or their representatives in planning or changing services, and decisions affecting operation of services.
- **Avoiding choice inequalities:** The need to avoid choice inequalities as health inequalities are already pronounced and entrenched.
- **Patients behaving differently:** Patients' Choice is one of the first NHS reforms to require patients to behave differently, so it is essential that the reform is carefully tailored to their needs to give them maximum and equal benefit.

Patients Choice is the point where individual patient involvement intersects with collective involvement. Patients are given an individual choice about where to go for treatment and at the same time they can influence the quality of care by abandoning hospitals which do not meet their standards. In order to ensure that such a process really empowers patients, it must be designed from their point of view. Furthermore, all population groups must be consulted about the issues for them in the reality of choice, to avoid setting up choice inequalities which empower some but merely disempower others even further.

1.3 Who will Choosing and Booking - excluded to start with? In many cases, people using the Choose and Book system will already be struggling with some sort of disadvantage or exclusion, because such factors are associated with ill-health and are therefore likely to generate greater use of the NHS. Sometimes the disadvantage which makes them more dependent on the NHS, such as the disability of a chronic medical condition, may be the very factor which puts them at risk of exclusion from Choose and Book. The Choice system must therefore be shaped round the needs of such patients. Various types of disadvantage can be excluding factors.

1.3.1 Exclusion from Patient Choice through personal disadvantage

i) Older people (over 65) account for 9.4 million people or 16% of the UK populationⁱⁱⁱ, yet they make up almost two thirds of patients admitted to NHS hospitals^{iv}

- just over 20% of people between 50 and 64 suffer from a long term illness or disability which limits their daily life, rising to almost three quarters in the over 85s.
- 28% of people over 65 reported difficulties with their eyesight and 32% reported difficulties with their hearing
- 53% of such households had a car compared with 80% of other households. Access to a car drops to 28% for over 65s living alone^v

Choices made by such patients might exclude distant hospitals or those which are not disability-friendly. They might also find themselves excluded from the Choose and Book process because of sight or hearing impairment.

ii) Care Home residents – 4% of the population over 65 live in care homes.^{vi} In 2000^{vii}, compared to the same age group living at home, those over 65 in care homes over the preceding 12 months, were

- more likely to have been an inpatient, (23% instead of 15%)
- less likely to be have been an outpatient (33% instead of 43%)

Care home residents are completely dependent on care home staff for information and support and are at risk of exclusion from Choose and Book unless the process is shaped to their needs.

iii) Carers - 2.8 million people aged over 50 provide informal care with one in four of these providing over 50 hours per week caring. One in five people in their fifties are providing care^{viii}

The complexities that many carers have to juggle in their daily lives will influence their choice of hospital, information needs and the logistics of the whole Choose and Book process for them, whether as a patient themselves or as carer for a patient.

iv) Disabled people - There are 8.5 million disabled people in the UK or 14 % of the population. Disability includes long term mental illness. 2.75 million have a significant hearing impairment and 2 million have a significant visual impairment. ^{ix} Because of associated unemployment, disabled people are likely to be on lower incomes.^x

Disabled people are therefore at risk of exclusion from Choose and Book process unless it is fully compliant with their needs and they can be satisfied that prospective choices of hospital will be accessible to them, even though their disability may increase their use of NHS services.

v) People in lower socio-economic groups suffer deprivation which is associated with ill health and therefore greater dependence on the NHS. Comparison between unskilled men and men in professional groups^{xi}, for example, shows

- Deaths from coronary heart disease are twice as high
- Deaths from lung cancer are four times as high

Low income may exclude certain distant hospitals from the choices people in these groups can make, because of travel costs, while costs associated with information (such as internet call charges) may inhibit access to information to make choices.

vi) People from certain ethnic groups have higher death rates for some conditions

- Death rates from coronary heart disease are roughly 40% higher among people born in South Asia than among those born here^{xii}
- Death rates from stroke are two thirds higher among Black Caribbean men than among other men.^{xiii}

Existing language and cultural barriers to services may be aggravated by the same barriers in Choose and Book. People from such ethnic groups are at risk of exclusion if the process does not recognise their needs and provide information about whether hospitals meet those needs.

1.3.2 Exclusion from the Choose and Book process through Information disadvantage - It is claimed that about one third of people relate best to the spoken word and two thirds to written information. Within those parameters will be those who relate best to the spoken word, but have hearing difficulties, and those who relate best to written information but have impaired sight. Certain other groups suffer similar information disadvantage:

i) Those who do not have English as their first language in either group will need their needs met in their own language but may suffer a double barrier if they cannot read in their own language or also have hearing or sight impairments. This is a barrier to using the Choose and Book process and in accessing information.

ii) People with Basic Skills needs may find it difficult to access information in written format. There are 7 million adults nationally with literacy and numeracy skills below those expected of an average 11 year old. In London almost 23% of 16-60 year olds have poor numeracy and literacy^{xiv}. There is a strong association with deprivation so in Tower Hamlets for example, the most deprived borough in London, total poor literacy and numeracy is over 31% for this age group. The tasks tested in the national survey from which these figures were extrapolated have similarities with the Choose and Book process. They included

- Interpreting a newspaper advert
- Getting information from Thompson's Directory
- Reading a train timetable
- Reading a medicine bottle
- Reading a recipe

iii) People without access to the internet Figures for access to the internet, whether at work, home or elsewhere show that internet access is growing rapidly, but is bringing its own inequalities. The latest figures from the MORI (February 2004) Technology Tracker show that 54% of the UK population use the internet at home at work or elsewhere, but with wide variations in social class

Social Class AB - 76%
Social Class C1 - 63%
Social Class C2 - 48%
Social Class DE - 30%

The inclusion of internet access at work may be misleading as it does not mean that patients could use the internet to get information for Choice or do E-Booking.

Certain population groups are particularly disadvantaged in access to the internet:

- **Older People:** Only 25% of over 65s and 14% of over 85s have internet access at home. *'While older people stand to benefit most from the IT revolution they are less likely than most younger groups to get online. The reasons for this are not straightforward and may include insufficient income, difficulties with vision and hand movements, or a perception, if they did not use IT at work or at school, that IT is irrelevant to them.'*^{xv}
- **Disabled People:** the Joseph Rowntree Report *Disabled people and the Internet: Experiences, barriers and opportunities*^{xvi} noted that people with disabilities may have stronger needs for IT but seem to have a lower usage rate and that these needs 'will become more urgent' as the government December 2005 target of putting all government information and transactions online approaches, despite the commitment to maintain 'traditional' methods.

Clearly, lower socio economic groups, disabled people and older people are at risk of exclusion from Choose and Book if it is exclusively dependent on web based information and processes.

iv) People without access to Digital TV: 45% of the population use digital TV^{xvii}, but like internet access this differs greatly across social classes:

Social Class AB – 48%
Social Class C1 - 46%
Social Class C2 - 50%
Social Class DE - 39%

The Department of Health undertook two pilots using digital TV to allow people to book GP appointments in the West Midlands (the Living Health project) and NHS Direct piloted an interactive television channel to provide information about particular illnesses and conditions (the Communicopia project.) The Evaluation

^{xviii}found evidence that Digital TV 'may help provide a service to people who might otherwise be excluded.'

v) People without access to their own telephone: Around 93% of households have access to a telephone, a much higher rate than access to the internet or digital TV. However, in areas of high deprivation, 12 % have neither a mobile nor fixed phone.^{xix} Such groups would be at risk of exclusion from a Choose and Book system involving use of a Call Centre, as low income would act as a barrier to using a payphone, the impracticality of which would also be a disincentive to use the process.

These factors demonstrate the importance of ensuring the accessibility of the Choose and Book process and the need for effective patient and public involvement as one means to that end. The best way to design new services is to involve all the different likely user groups from the start in the process.

1.4 Objective of Taking Soundings: Taking Soundings is a patient and public involvement exercise undertaken on behalf of the LPCP to inform the planning, design and operation of Choice at Referral. Its purpose is to gather data on the reality for a diverse range of population groups, of the Patients Choice reform. In addition to providing a 'patient reality check' on the development of the policy pan-London, Health Link was commissioned to develop advice for the LPCP and the National Programme for IT (NPfIT) programme on how best to support patients in Choice and address the access issues relating to E-Booking, providing a learning resource for London Primary Care Trusts to draw on when they commission Choice at the point of referral. This was not intended to be a robust academic piece of research but a patient and public involvement exercise, giving participants the chance to influence the design of this reform, by gathering their views and feeding them into implementation. Questions to be tested in this process, particularly for 'hard to reach groups', were:

1. What information would patients want to support them in making Choices?
2. What would be the most credible and practical source of that information?
3. How accessible would patient groups find the Choose and Book process?
4. How could any barriers identified be overcome?

ⁱ *Building on the Best: Choice, Responsiveness and Equity in the NHS* Department of Health Dec. 2003

ⁱⁱ Section 11 of the Health and Social Care Act 2001

ⁱⁱⁱ General Household Survey 2001

^{iv} *Older Peoples National Service Framework* Department of Health March 2001

^v General Household Survey 2001

^{vi} Census 2001

^{vii} Health Survey for England 2000

^{viii} Census 2001

^{ix} Disability Rights Commission

^x *Disabled people and the Internet: Experiences, barriers and opportunities* Joseph Rowntree Foundation Pilling, Barrett and Floyd May 2004

^{xi} *Securing Good Health for the Whole Population: Population Health Trends* Wanless Dec. 2003

^{xii} Ibid.

^{xiii} Health Survey for England 1999

^{xiv} Basic Skills Agency figures 1996 -1997. Basic skills Survey Results of Adults 2002/2003 awaited

^{xv} Gordon Lishman, Director General of Age Concern E-envoy Press release on Getting Started Campaign 2003

^{xvi} Disabled people and the Internet: Experiences, barriers and opportunities Joseph Rowntree Foundation Pilling, Barrett and Floyd May 2004

^{xvii} Mori Technology Tracker February 2004

^{xviii} *First steps towards providing the nation with health care information and advice via their television sets- An evaluation of pilot projects exploring the health applications of digital interactive television* City University Report to the Department of Health December 2002

^{xix} *Consumers' use of fixed telephony* Q14 August 2003/27 OFCOM October 2003

2. HOW THE PROJECT WAS CONDUCTED

2.1 Approach taken: In January 2004 Health Link recruited some 21 lay people experienced in patient representation from its database of 120 ex London Community Health Council members, 17 of whom are Patients Forum members. These formed a Choose and Book Patient Reference Group together with the patient and public involvement leads for London's five strategic health authorities, Sue Wales the then Project Manager for Project Delivery and Assurance for London Patient Choice and a representative from the London office of the Commission for Patient and Public Involvement in Health. Membership is given at Appendix 1. The process began with an Information Event to familiarise members with Patients Choice and start testing the policy against their perspective. The outcome of the Workshops held on the Information Day is set out in Appendix 2.

2.2 The Choose and Book Patient Reference Group: the Patient Reference Group advised on a number of London and national issues including:

1. The type of information patients want when choosing between hospitals;
2. The wording of an advertisement to raise Choice awareness in London;
3. The patients' perspective on electronic booking, tested in scenarios;
4. Possible parameters for transport availability;
5. Scripts used by Call Centre staff when patients ring to book appointments;
6. The format and content of the national Choose and Book website.
7. 'Road testing' the Call Centre on a given testing day

A summary of this material is included at Appendix 3. The Choose and Book Patient Reference Group decided that further work was necessary to ascertain the views and needs of 'hard to reach' groups. The resulting *Taking Soundings* exercise triangulated the views of the NHS on information and accessibility against those of the Reference Group and then against 'hard to reach' groups.

2.3 Taking Soundings from people not 'at the table': The objective of the next phase of the patient and public involvement work was to 'take soundings' from hard to reach groups on what information would be important for them in making choices and on any barriers to them in exercising that choice.

Two additional objectives were identified from the perspective of voluntary sector organisations and community groups engaging in Taking Soundings:

- To contain the amount of information to the minimum required to make sense of the question, rather than overburden groups already hard-pressed with their own work and relentless requests for consultation responses.
- To be as flexible as possible in how the responses were gathered, rather than setting up a meeting and expecting groups with limited resources and time to attend.

2.3.1 The Taking Soundings Response Form: To meet the objective of keeping information provided to a minimum, a stage by stage description of the Choose and Book process was developed by Health Link jointly with Sue Wales of the NPFIT team, which sought to present the issues from the patient perspective, not the NHS perspective. The resulting Taking Soundings response form we used comprised

- an introduction explaining the five stage Choose and Book process as currently planned
- five further sections each with a diagrammatic representation of each stage and explanatory text,
- a total of seven open questions and two closed across the five sections
- an evaluation form

This Taking Soundings form is attached at Appendix D.

2.3.2 Self selection of method of using the Taking Soundings form: 19 Taking Soundings responses were received in all, from the organisations detailed in paragraph 2.4 below. To offer flexibility to the voluntary and community groups, shaping the process to their needs and working methods, we explicitly gave them the option of how they wished to respond, providing that the Taking Soundings form was used. This resulted in the following methods of completing the form (figures in brackets are the numbers of responses falling into this category)

- Self completed Taking Soundings forms (9),
- Semi-structured telephone interview by Health Link with an individual member using Taking Soundings form as the brief (2)
- Group interviews facilitated by Health Link staff using Taking Soundings form as the brief, held at the organisation's premises with people supported by the organisation (6)
- Two groups sent in comments relating to some of the issues raised in the form, rather than completing the form (2).

In one of the groups sending in comments, a Taking Soundings form was completed by a staff member with a group of self advocating people with a learning disability, but never reached us. Comments subsequently made by two staff members on the issues raised were included in the Findings.

Respondents to the self completed forms would have included staff with personal experience of relevance despite being employees rather than volunteers. In some cases, the voluntary organisations and community groups we approached are run by volunteers, in others by staff or often by a mixture of the two. Our objective was to involve specific sections of patients and the public in issues relating to Choose and Book – to take soundings from people on what the reality of choice might be for them. We did not therefore record the precise status of participants as we felt that distinctions between staff and members would be artificial for this purpose. In three of the group interviews, one staff member was present in each case and contributed to the discussion.

2.4 Groups contacted: As *Taking Soundings* was a patient and public involvement exercise rather than a formal academic study, we did not use formal sampling methods to select the individuals who completed the Taking Soundings form. Instead we developed a convenience sample of population groups at risk of exclusion from Choice and then identified community groups and voluntary organisations who work with them, through our existing networks. This sample should not therefore be seen as strictly representative of the views of those at risk of exclusion from choice.

The organisations listed below, with the groups with whom they work, method of participation and numbers responding, were successfully contacted by post or email. Where individual contacts within organisations were not known, we established initial contact by telephone to explain the project and subsequently send the Taking Soundings form by post or email.

Where one self administered form was returned, this is recorded as one individual responding, as the numbers contributing to the organisation's response are not known.

Organisation and Location	Relevant Group	Nos.	Method of Participation
Action for Sick Children 5 groups/ families	Families with sick children	5	Self administered TS Forms
Alzheimer's Society Hammersmith Enfield	Carers Support Groups	21 (First Group) 9 (Second Group)	Face to Face semi-structured group interviews
ATD 4th World Walworth	Families living in poverty	5	Face to Face semi-structured group interview
Brent Multi-Faith Forum	Faith communities (responses on Islam and Hinduism)	2	Semi-structured telephone interviews
Contact a Family London	Families with disabled children	1+	Self administered TS Form (by Helpline Managers)
Counsel and Care London	Older People and Carers	1+	Written Comments on issues raised in Taking Soundings Form (by several managers)

Greenwich Association of Disabled People	Disabled People	1	Self administered TS Form
Heston House Care Home Hounslow	Care home residents including BME residents	19	Face to Face semi-structured group interview through an interpreter
The Katherine Low Settlement Pensioners' Club	Older people	4	Self administered TS Form
Mencap London	People with a Learning Disability	2	Written Comments on issues raised in Taking Soundings Form
Southwark Mind Southwark	Mental health service users	2	Face to Face semi-structured group interview
Thames Reach Bondway Stockwell	Homeless People	19	Face to Face semi-structured group interview
UK Youth Parliament	Young People	1	Self administered TS Form

In all some 92 people considered these issues in individual responses or group discussions. Where we held group interviews, the response from the organisation reflects the consensus view arising from the discussions.

2.5 Organisations not responding: Another 42 organisations were contacted by letter and email with extensive telephone follow-up, but for one reason or another were unable to assist. This may be symptomatic of the 'consultation fatigue' which dogs the voluntary sector. In fact in two cases, large national voluntary organisations initially refused to engage in any more health consultation, as they felt it made no difference. After further discussion, they did agree to participate. In other cases, we were dependent on our networks of contacts with various voluntary sector groups and for personal recommendation from the lay members of our Patient Reference Group to procure meaningful engagement.

2.5.1 Black and Ethnic Minority Groups: As we had great difficulty in engaging with black and ethnic minority people, we secured funding from the Department of Health to commission Black Londoners Forum to run some focus groups on the Taking Soundings issues. Black Londoners Forum is an umbrella organisation with a membership of over 900 black and ethnic minority voluntary and community

groups. The Forum acts as the recognised interface between the GLA and London's black community. This work is on-going and will be produced as a supplement to this Report.

2.6 Literature Search: there are a number of interesting studies which are relevant to the topics covered in Taking Soundings.

i) The quality of Information to patients: The Consumers Association^{xx} has defined a patient's information need as '*an individual's capacity to benefit from information*' and set out ten core attributes for information to patients

- Accessible
- Accurate
- Appropriate
- Consistent
- Current
- Evidence-based
- Impartial
- Timely
- Transparent
- Understandable

ii) Information Overload: "What do I have to know, and how do I know I have to know it?"^{xxi}: Lessons from the business world about information overload indicate that this can be disabling. A Reuters survey in 1996^{xxii} of 1300 managers found:

- Forty-three percent said they had trouble making important decisions because they had too much information.
- A third said they suffered from stress-related health problems brought on by too much information.

iii) Disability and Choice of services: The Disability Rights Commission survey on Access to Services^{xxiii} for disabled people examined views of disabled people on access issues in public and private sector services and concluded that

- For people who use a mobility aid, aspects of the physical environment such as steps at the entrance to buildings, and heavy internal and external doors, can be barriers to use of a service.
- To those with sensory impairments, physical barriers such as misleading signage and a lack of hearing loops are also important.
- Staff attitudes or behaviour were barriers for 14% of disabled people surveyed, rising to 24% for those with sensory impairments.

'This survey shows that disabled people have influence over friends and family as customers or service users. The majority of respondents (70%) said that their family or friends would consider using alternative services when informed of access difficulties.'

iv) Call Centres across the public sector: In December 2002, the National Audit Office examined Call Centres across the public sector^{xxiv} and found

- *'60 per cent of respondents were content to receive advice and services from departments over the telephone, though younger people were more likely than older people to be willing to receive goods and services in this way.*
- *For the remaining 40 per cent, the main reasons why they were unwilling to do so were because*
 - *they preferred to deal with someone in person (17 per cent);*
 - *they had either tried telephoning and could not get through or found the service they had received to be unacceptable (8 per cent);*
 - *they wanted to receive information in writing (6 per cent).'*
- NHS Direct was the most expensive of the 133 public sector Call Centres examined, at £114 million
- Costs of the 133 Public Sector Call Centres studies ranged from 60p per minute to £5 per minute
- *'Research in 1999 (People's Panel Telephone Wave 3, Cabinet Office, April 1999) found that only half the population thought that it was reasonable to wait over 30 seconds for a call to be answered and 20% expected a call to be answered within 15 seconds.'*
- Only 14% of public sector Call Centres advertise their services in telephone directories, although this is where those without access to the internet, will look
- *There is 'a risk that some [quality] indicators can have an unintended effect for example, where Call Centres have a target to answer calls within a certain number of seconds this may result in staff devoting less time to each call to be able to answer calls more quickly. It is important that people should feel that they had the opportunity to speak to another human being and that their call was given serious consideration.'*

(v) NHS Direct: the National Audit Office also studied NHS Direct in 2002 and found

- *'Only some 51 per cent of those aged over 65 were aware of NHS Direct. And while 70 per cent of the population, rates the service as useful, among over 65s this falls to 61 per cent. This is despite the fact that older people are more likely than others to require healthcare advice, and they may benefit especially from telephone access from their domestic setting.'*
- *'Awareness of NHS Direct is also lower among ethnic minority groups - in May 2000 this stood at 45 per cent for ethnic minorities against 52 per cent of the population...Research has shown that people without English as a first language are significantly disadvantaged in discussions about medical conditions.'*
- *'NHS Direct's interpreting facilities have been used sparingly to date - only about 1,000 times during 2000-1 out of a total of 3.5 million calls. Our estimates suggest that over 600,000 people prefer to receive medical advice in Asian languages alone'.*

vi) Call Centres in Local Government: In 2000 the Foundation for Information Technology in Local Government researched the practical experience from local government in establishing and running Call Centres. Its Report, *Making Contact*,^{xxv} noted the continuing importance of Call Centres despite the availability of the internet:

- *'Typically, local authorities report that about three quarters of the daily contact they have with citizens currently comes in via the phone. The phone remains the preferred contact method for people who are unable or unwilling to visit council offices in person and is likely to remain so, despite the rapid growth in Internet access'*.
- *'Typically, 25 per cent or more of calls are lost before being answered as callers fail to reach their intended destination or ring off. Call losses of over 50 per cent have been recorded for local offices in some authorities. Although not directly comparable, well-run private sector Call Centres (and indeed some local authority Call Centres) aim to lose less than five per cent of calls'*
- *Although access to the telephone is high within the general population, not all local authority citizens and users have a phone. Academic research has suggested that in some areas of social deprivation less than 50 per cent of households may have a telephone. Disconnections are likely to be concentrated heavily in areas where the social needs are greatest. One London authority found that less than 30 per cent of households in one area of the borough had a fixed phone and that mobile telephones were not compensating.*

vii) The use of the internet and socially excluded groups: three recent reports from the Joseph Rowntree Foundation give a useful insight into this issue:

a) Disabled people: the recent Joseph Rowntree Report *Disabled people and the Internet: Experiences, barriers and opportunities*^{xxvi} noted the many assistive technologies available to disabled people for the internet but also pointed out *'the more fundamental problems of obtaining long term Internet use for those who do not have, do not know where to obtain advice about and cannot afford assistive devices, or those who need training to use a computer, cannot afford a computer, or are worried about or cannot afford online costs. Nor will it help those who do not have friends and relatives to help them set up internet access. It is these practical problems that need to be solved'*.

b) People living in sheltered housing: Research by the Foundation^{xxvii} on internet access for older people living in sheltered housing found some potential for this medium to develop further:

- A minority of older tenants were interested in trying the Internet.
- Some were helped by community support workers or family members.
- Others would like training on how to navigate the Internet.
- For many older tenants unfamiliar with computers, Internet access depended on assistance from experienced users.

- *'Tenants were at best ambivalent towards the idea of online access to services. Most saw it as a substitute for physical activity and human contact, and a threat of further isolation.'*
- *'Some felt that services enabling the continuation of everyday routines (such as shopping for food) or providing support (for example, transferring prescriptions) could be useful to homebound people'*

c) People using community IT facilities 6000 UK Online Centres have been established by the government, many of them in libraries. A Review by the Foundation of community IT facilities^{xxviii} found:

- *'Use of public access and support sites by those currently perceived as excluded from the benefits of ICTs is generally low.'*
- *'The location of many public access sites in libraries, schools, further education colleges and other public-sector venues may be a significant barrier for those who do not associate such institutions as being part of their lives.'*

^{xx} *Patients Information – What's the Prognosis?* Consumers Association January 2003

^{xxi} *Impact of Too Much Information - Handling Information Overload* George Siemens October 26, 2002 www.elearnspace.org accessed on 20.7.04

^{xxii} *Dying for Information? An Investigation into the Effects of Information Overload in the UK and Worldwide.* 1996. Reuters Studies.

^{xxiii} *Access to Services Report on Findings* Disability Rights Commission January 2003

^{xxiv} *Using Call Centres to Deliver Public Services* National Audit Office December 2002

^{xxv} *Making Contact* Foundation for Information Technology in Local Government 2000 www.fitlog.com

^{xxvi} *Disabled people and the Internet: Experiences, barriers and opportunities* Joseph Rowntree Foundation Pilling, Barrett and Floyd May 2004

^{xxvii} *Internet access and online services for older people in sheltered housing* Maria Sourbati Joseph Rowntree Foundation February 2004

^{xxviii} *Challenging the digital divide? A Literature Review Of Community Informatics Initiatives* Joseph Rowntree Foundation Loader and Keeble May 2004

3. FINDINGS

Findings are divided into two sections:

Choosing where to be treated

- What information patients need when choosing a hospital
- How would they like to access this information

Choosing when to be treated

- How accessible would they find the Choose and Book process
- Issues about the Telephone Call Centre

Key themes and discussion are set out below. The comments in text boxes are included to illustrate why certain information is important to patients. Where quotation marks are included, these are direct quotes from participants. In other cases, they are comments derived from the Response forms. Text Box titles indicate the issue and the caption the group raising it. There has been no attempt to weight or prioritise the issues, as this was patient and public involvement exercise not based on robust sampling methods.

Information on which groups raised which issue is found in Appendix 6, *Who said what?* Information topics which came up again and again were

- access issues relating to transport,
- quality information such as mortality rates, cleanliness, hospital acquired infection rates, quality of nursing care, skills and training of staff on various topics, and reputation of surgeons,
- hospital or ward policies such as whether staff feed patients who are physically frail, whether relatives can bring in food for patients, and follow-up care
- subjective issues such as hospital and staff reputation (although this was not defined) and whether staff are caring

Some of the information specified is unlikely to be available currently and some relates to the aspirations for quality of service which may not be easy to produce. For example, the need for a Confidential Enquiry was mentioned, into the premature deaths of people with learning disabilities die from treatable illnesses. On the basis of Taking Soundings, the drive to improve quality in the NHS is as important to patients and the public as having Choice

Care Home residents whose first language is not English

These patients are heavily dependent on family and relatives for information, opinion and support. Some will not even accept a change of prescribed medicine without checking with their family.

Heston House Care Home

3.1 General comments on Choice at Referral: this project was not designed to elicit views about the choice policy but about the mechanics of Choice at Referral. However, most

groups were positive about the new opportunities, particularly about choice of times and dates. General comments made were:

3.1.1 Aspects of Choice of Hospital

- For Choice to really work, users need to be involved in driving up the quality of care in *all* hospitals
- Local knowledge of hospitals would affect choice of where to go.
- Some users would prefer to choose their local hospital for the sake of familiarity irrespective of its quality, although this should not be assumed.
- Waiting time was seen as an overriding factor by some.
- Waiting time would be balanced with proximity
- Older people visiting patients frequently should not be burdened with long journeys.
- A minority of patients would only be confident if they went and looked at a hospital before choosing it
- All the stress of finding out you have a serious physical health problem requiring surgery and then worrying about the choice of where to have it, that people who are not mental health service users feel, is aggravated for people who have mental health problems.

3.1.2 Aspects of the Choose and Book process

- Many participants emphasised the stress and trauma of illness as an important factor in the accessibility of Choice. This might be induced by the circumstances of the patient (being already very vulnerable or dependent, or not having English as a first language) or the worry about a particular procedure they are facing or the on-going trauma of a chronic condition for the patient or their carer or family. These feelings and emotions underlie all responses to the Choice process.
- The experience of participants who are regular users of the NHS led them to question how this process would work when grafted onto the reality of the NHS as they know it:
 - Operations are frequently cancelled at the last moment, with some hospitals in South London even warning patients in writing that their operation might be cancelled after they had been admitted and started preparing for the surgery, which was very stressful.
 - On this basis might one find an operation at a hospital one had carefully chosen, cancelled at the last moment – where would that leave the patient?

3.2 CHOOSING WHERE TO BE TREATED

3.2.1 The Information Patients need when choosing a hospital: the information specified by respondents for them to make choices falls into several categories:

i) Facts on Access – information relating to practical access, such as how could they get there, wheelchair accessibility, waiting times, car parking costs.

ii) Facts on Quality – information to judge the quality of the hospital, such as numbers of agency staff and hospital acquired infection rates

iii) Hospital Policies – policies and practice of the hospital or ward which would affect patient experience, such as willingness to involve carers or allow parents into the Recovery Room after children's surgery.

iv) Attitude and subjective issues – issues about hospitals which are difficult to measure or can only be judged subjectively, such as quality of nursing care and levels of respect and dignity.

i) Facts on Access: Certain hard facts on the accessibility of a hospital, both generally and for the particular circumstances of some patients, were specified as important to inform choice of hospital. We were told that older people, for example, will need to know exactly where the hospital is, with a clear and readable map and clear instructions about parking, disabled parking and buses/trains and how to get to the department they need. Costs should be paid up front to people on benefit perhaps by sending them Saver Tickets

a) Transport: For certain groups of patients, how they get to hospital was identified repeatedly as a very important factor. It is difficult to overstate how important this issue is, particularly for people who are frail. Certain groups who expressed heavy reliance on their families, such as older people, would want the hospital to be accessible for them to visit daily. Asian families and those of the Hindu and Muslim faiths in particular cited the family as central to their faiths and culture, and would want family and community members to visit daily. Items of information required fall into three categories:

- Getting to hospital by public transport
- Using hospital transport systems
- Driving to hospital

Public transport

- Details of how to get there,
- Walking distance from bus stops or station,

Carers and Access

Carers visit frequently and many are older people and some are disabled themselves. Travelling time and cost and distance to walk from the bus stop are all factors. Alzheimers Carers Support Group

Poverty and Patient Experience

Effectively, because visitors are not reimbursed, patients' relatives could not visit them at all, if they could not afford the parking or the fare resulting in great isolation for patient. ATD 4th World.

- Cost of getting there
- Availability of reimbursement of fares

Using hospital transport systems

- Quality of Hospital transport
- Whether hospital transport staff are trained
- Whether transport is comfortable
- That hospital transport is frequent and routes direct
- Whether priority is given to certain patients for hospital transport
- Waiting times for the return trip

Older People and Hospital Transport

“Older people are collected early in the morning for a midday appointment and not dropped home until late afternoon because transport is limited. This is not acceptable for people who may have diabetes and need regular meals.”

Counsel and Care

Older People and Transport

“Another issue is continence: people may become distressed at the thought of not being able to get to the toilet. For these reasons some older people may cancel or be reluctant to keep the appointment. If Choice is to work properly, the choice of effective and efficient transport is a must.”

Counsel and Care

Driving to Hospital

- Car parking facilities (24 hour-capacity available by visiting time?)
- Cost of car parking (£2.50 per hour charged by some is too much)
- Reduced parking charges for parents of sick children?

b) Access to treatment:

- Waiting times for the procedure
- Waiting times for each procedure if more than one.

c) Disability Discrimination Act Compliance

- Hospital environment, processes and staff skills need to ensure overall compliance with the Disability Discrimination Act.
- For example, patients with learning disabilities require longer appointments, accessible information and access through appropriate signage.

ii) Facts on quality: many groups specified particular items of data they would want to know to inform their judgement of a particular hospital. One child patient support group pointed out that if one of the options offered were to be a private hospital or independent Treatment Centre, information needed would be different. Most topics would clearly need comparative data with London or national rates so patients could make sense of them. Apart from certain general performance information which came up in discussion, this sort of information falls into two categories, environment and staff:

Cleanliness

After a very bad experience, one participant had taken in her own bleach and cleaning materials when admitted.
ATD 4th World

a) General performance information:

- Star Ratings
- Patient Survey results
- Mortality rates
- Number of last minute cancellations
- Cleanliness standards
- Rates of hospital acquired infection, including food poisoning rates
- Doctor to patient ratio

b) Environment:

For all patients, does the hospital have -

- All single sex wards (certain faiths would not use mixed sex wards under any circumstances)
- Single rooms as well as multi-bedded (ratio)
- Bed side telephones
- Bedside TVs (What does it cost to use them?)
- Bedside radios
- Wards which are not 'worryingly' large
- Arrangements for confidential consultation on the wards
- Prayer space for Muslim patients and visitors to pray 5 times a day. Muslim refugees new to Britain would require a separate prayer space but British born Muslims are more likely to accept shared quiet space including area with prayer mats facing Mecca.
- Smokers' areas for patients
- Disabled access within the hospital (e.g. wheelchair accessible toilets on wards,)
- Textphone (such as Minicom); Videophone
- A reasonably priced canteen
- Information provided to patients which
 - Covers how to complain and to whom
 - Covers any recent improvements
 - Covers availability of prayer spaces and chaplaincies
 - In minority languages (which ones?)
 - Is available in Braille and on audiotape
 - Accessible to those with learning or other disability

Environment

Environment was seen as of prime importance as it influenced how people felt in general. This did not mean new hospitals, which were sometimes dirty, but the overall feel of the place.

ATD 4th World

Smoking

Are there smokers' areas for patients? To be able to smoke without being discriminated against, especially when fasting, is important

ATD 4th World

For children as patients and their parents, does the hospital have:

- A dedicated children's ward
- Facilities or accommodation for adolescents
- Facilities for parents to take a break or make refreshments

- Accommodation for parents to stay
- Education provision
- Facilities and equipment for disabled children or those with special needs
- Information provided to patients which is
 - designed for children
 - covers details of local facilities (shops, canteen etc.) for parents
 - covers details of accommodation available locally for parents

Prayer

“Use of the prayer space is very important for Muslims, especially for long term patients (patient and carer pray together).”
Brent Multi-Faith Forum

c) Staff

Staff Skills in Dementia

“Are staff trained in the needs of dementia patients or do they just treat them as stupid?”

Alzheimers Carers' Support Group.

Staffing information affecting all patients:

- Numbers of staff compared to optimum recommended standards
- Rates of staff turnover
- Numbers of agency nurses
- Enough staff of the right level to provide personal care
- Whether wards have Ward Housekeepers
- Whether hospitals have Modern Matrons
- Healthcare interpreters/advocates for people whose first language is not English
- Whether there is a mental health liaison system?

(NB References to ‘bringing back Matron’ and having someone to be in overall charge of the state of the ward, were translated in discussion as having Modern Matrons and Ward Housekeepers respectively).

Staffing information for children and parents

- 24 hour on-site paediatric cover
- Play provision with qualified play specialists

Staff training and Skills affecting all patients:

- Consultant expertise and reputation (may be overriding if a serious condition)
- Skilled in English speaking
- Are staff trained in
 - the needs of dementia patients
 - confidentiality of patient's personal and medical information
 - the needs of mental health services users suffering the effect of anaesthetics.
 - cultural awareness e.g. the significance of a patients' faith and how this can help to motivate and inspire patients in dealing with their condition.

Staff Skills in Childhood Conditions

“Do medical staff have expertise in particular areas? Very important for families caring for children with rare conditions, as they are often referred, only to be referred again as the right expertise is not available.”

Action for Sick Children

- Disability equality, including support and training involving people with learning difficulties and physical disability.

Staff training and Skills affecting children and parents

- Are staff trained in needs of children with special needs or disabilities

iii) Information about Ward and Hospital Processes

a) Ward Processes

Affecting all patients

- Are patients allowed to come and look round the ward before admission?
- Is there occupational therapy provision?
- Is culturally appropriate food available?
- Is vegetarian food available?
- May relatives bring food in for the patient if hospital food not palatable?
- Do staff feed patients who cannot feed themselves?
- What is the quality of post operative care?
- Is self-administered pain relief available?
- May patients use alternative pain relief e.g. aromatherapy, without difficulty?
- What are security protocols to stop patients with dementia wandering off?
- Is the key role of carers and families for people with dementia recognised?
- Are carers offered a choice about being involved in the patients' personal care or are they obliged to do so because of staff shortages or prevented from doing so because of policy?

Culturally Appropriate Food

"How ever many times you tell them they always revert back to old practices, if you are ill, curry and rice is not a good idea, it is too spicy. Hospital caterers seem totally unaware and think BME patients just want curry and rice."
Brent Multi-Faith Forum

Affecting children and parents

- What are security protocols to stop child patients wandering off?
- Are parents also provided with food?
- If so, how much do they have to pay?
- Are parents allowed to sleep in a bed next to the child?
- May siblings visit too?
- May a parent bring in a child's favourite food?
- Are there Children's menus?

Consent Procedures

"Do staff give all the information and possible side effects before seeking signature – or is it a case of 'just sign here' "
ATD 4th World

b) Hospital-based processes

Affecting all patients

- What are the Visiting Hours?
- How many visitors are allowed
- Are visits allowed outside designated hours?
- Is part of the chapel set aside for Muslim patients on Fridays?
- Is there occupational therapy provision?

- What is the hospital record on keeping to appointment time?
- Who provides follow-up care after discharge (should be the local hospital no matter where procedure took place)?
- Is there support after discharge?
- Is psychological support available if needed?
- Would the Care Co-ordinator or Community Mental Health Team for a patient using mental health services be informed on progress of care?
- Do nurses pick up doctors' prescribing errors?
- How involved are patients in choosing medication?
- Do they have good communication systems with the GP?
- Is post operative care/support available after discharge?
- What are the rates of lost notes?

Visitors

"BME communities often have a sense of duty to each other, therefore, not only the family members might visit, but members of their wider community, which means there can be many visitors."
Brent Multi-Faith Forum

Affecting children and parents

- Are parents involved in care, care plan and reviews?
- Will education provision be similar to school so there is continuity?
- Do play specialists reduce fear, use distraction techniques to minimise pain and anxiety and prepare the child for procedures?
- Is there a preadmission preparation programme?
- Are parents welcomed into the anaesthetic and recovery rooms?

iv) Information about hospital, staff attitudes or other matters which are subjective

Families of Sick Children and Stress

"Do they look after the child and family holistically, as stress affects people in different ways."
Action for Sick Children

a) Aspects of reputation

- Must be a hospital you can trust,
- A good reputation for treatment concerned
- Reputation of the surgeon
- Experience in providing a high level of care
- Ethos – welcoming and supportive to children and their families
- Good reputation in treating children with diverse conditions/special needs

b) Interaction with patients

- Do staff have a caring attitude?
- Is there respect for privacy?
- Is the nursing care of high quality?
- Do staff respect the patients' reliance on

Importance of Carers Role

"Doctors and nurses should be prepared to listen to carer' perspective and view as they know the patient."
Alzheimers Carers Support Group

their family for support and opinion?

- Is medical terminology used in a way parents can understand and digest?
- How well do staff administer the consent to treatment process?
- Are staff caring towards patients who are mental health service users?

c) Other Subjective Issues

- Is there a team approach to running the ward?
- Are both the child and the family treated holistically to minimise stress?
- Is it a comfortable place?
- Is the food of high quality?
- Is the post-operative care of high quality?
- Are administrators efficient?
- How caring are the consultants?

Mental Health Users and acute care

Because of their experience of sectioning and unpleasant treatments with side effects, these patients may be especially wary of medical interventions of all kinds.
Southwark Mind

3.2.2 How patients would like to access information

i) Alternatives information sources: Respondents were asked whether they would like to access information to help them make their choice of hospital from

- GP
- Information Sheet
- Independent Phone helpline
- IT in GP surgery
- IT at home/Library/Café
- Other sources

Other sources of Information

"..Maybe a parent who has been through that trauma, thus alleviating some of the fear and anxiety from the parent."

Action for Sick Children

Responses collated from the 19 Taking Soundings Forms received are shown in Figure 1. Participants were invited to tick as many options as they wished.

FIGURE ONE

CHOOSING WHERE TO BE TREATED					
QUESTION: As a patient or carer, how would you like to access the information you need?					
Options	From the GP	Information Sheet	Independent Phone helpline	IT in GP surgery	IT at Home/ Library/ Café
Yes	9	14	10	5	6
No	2	0	0	0	1
Multiple Options Selected			15		
Single Option Responses			2 : GP – 1; Other –1 (see below)		
Not Answered			2		
Suggested Other sources and numbers					
Media (1)		District Nurse/Health Visitor (1)		Patient Support group (5)	
Library (2)		Other Parent/patient (2)		Practice Nurse (1)	

Accessibility and authoritativeness of information is extremely important to respondents. A number of general themes emerged, together with specific comments detailed below:

Multiple sources of information

Computer access was likely to be for the few only. Discussion with the GP, written information and independent telephone support all being available would be the best solution in case the GP was not reliable, the Information sheet did not cover everything or further explanation was needed.
Alzheimers Carers' Support Group

a) ii) General Themes

b)

a) Time to Reflect- Many participants mentioned the need for time to reflect on the information given. Parents of children with complex needs would have to choose a hospital with a good record in all the conditions of the child, which could be complex

b) Provision of information from more than one source – this would be important because, as patients reflected on their various choices

- issues might come up which they wanted to know about
- they might want to check information already provided
- they might discover that information they wanted was not available, which might influence their choice
- greater flexibility would suit more people

Older People and the Internet access

“None of us have a computer at home, and would it impossible to use library and other IT facilities.”

Katherine Low Settlement Pensioners' Club Pensioners

A minority specified a second opinion, as the patient's trust may have been weakened by bad practice they had suffered in the past. On the other hand, a couple of people mentioned the risk of being overwhelmed with too much information.

validity of information from non-official sources. A significant number of participants specified that it must be independently produced i.e. not by the NHS Trust concerned and in some cases, not by the NHS at all. It was pointed out that

c) Authenticated information – there was scepticism about 'official' data as well as worries about the validity of information from non-official sources. A significant number of participants specified that it must be independently produced i.e. not by the NHS Trust concerned and in some cases, not by the NHS at all. It was pointed out that people need to be aware of the www.nhs.uk site and that it is an authenticated site, as there is much questionable information on the web.

Biased Information

“Any info is bound to have some bias on how good a hospital is.”

Brent Multi-Faith Forum

One participant had experienced a ward sister 'standing over' her while she filled out a patient satisfaction survey before discharge. Was this how all surveys were completed? The Healthcare Commission

was seen as sufficiently independent to provide/validate information

d) Overall need for personal support in making sense of the information

Most respondents referred to the need to have personal support in making choices from someone who did not stereotype them and was

- trustworthy,
- sensitive to their needs,
- non-judgmental.

For users of mental health services, dedicated psychological support would be required. One participant said that BME groups would not have the spare capacity to do the research for patients.

Stigma

“Users of mental health services are seen as incapable of knowing what they want. This is particularly bad for black users, who suffer double stigma.”

Southwark Mind

e) Providers of support - Groups mentioned as appropriate for this role included

- The GP practice nurse (better equipped to deal with parents in stress)
- Local older people's charities such as Age Concern
- Local groups supporting black and ethnic minority groups

- Independent groups used to empowering patients on their rights, who really understood the patient/carer perspective
- Self help groups, charities etc with a knowledge of a specific condition
- Local community organisations and groups for those from different faith and ethnic backgrounds
- In the case of children, another parent whose child has been through the procedure

f) Risk of greater dependency - Some participants noted that access to information for choice would inevitably be dependent on the support of someone else. This reliance would increase their overall dependence. Mental health service users, care home residents, patients with mental and physical disability dependent on an informal carer and children, are all dependent on their care givers (professional or otherwise) to help them interpret information. This role needs to be recognised and respected both by the GP and the hospitals.

GPs' time

GPs rarely have time to answer all patients' queries/anxieties now, let alone discussing options over hospital appointments.
Action for Sick Children

ii) Specific comments are grouped under the following headings

- a) Role of the GP as information provider
- b) Written Information
- c) Telephone support
- d) Web-based
- e) Other sources of information

a) Role of the GP – most groups were happy to have information from their GP but some were worried about this because

- Patients may have complained about their GP, which might prejudice them
- Some GPs have 'an attitude' to women carers.
 - Patients might not have a good relationship with their GP
 - Not all patients trust GPs' advice on choice of hospital
 - This process would give GPs too much control
 - It was a waste of the GP's time to be discussing aspects of different hospitals with patients in the precious seven minutes of the consultation
 - Patients might not have a good relationship with their GP
 - Not all patients are confident in their GPs' advice on choice of hospital
 - Dialogue with GPs might pressure patients feel into a choice, worrying about holding up a waiting room full of other patients.
 - Some GPs are not very responsive to the family's needs

Role of the GP

A Dutch participant noted that in Holland, the patient is given the phone number to ring and make their own appointment. The current British system was seen as patronising to the patient and illogical with a medically qualified person carrying out an administrative task.
Alzheimers Carers Support Group

- Requirements for how the GP should perform this role were mentioned, including
 - giving the patient plenty of time and support,
 - providing information in 'a patient and unhurried manner'

However, most groups mentioned the GP as the last resort if they were in any doubt. This obviously has capacity implications for GPs.

b). Written Information comments were made about format, content and availability

1. Format – written information needs to be available

- in other formats such as audio, video and braille
- in large print for those with sight impairment (size 14 font, bold Arial, 1.5 spacing)
- in minority languages
- In a suitable format for children including actual photographs of wards and play facilities
- In a suitable format for those with learning disabilities
- For patients not literate in their own language, written information in English will be translated by their family.

2. Content – certain aspects of content were seen as important

- Should include content to aid decision-making (i.e. a flow chart explaining 'How to make the right decision')
- Must be written in Plain English
- Pictures or diagrams to illustrate would be useful
- A 'Tick box' system would be useful to show what is available in a hospital.
- Should include comparative information so patients can judge the data

3. Availability –

- Written information should be available in the public library.
- Sheets should be provided that patients could take away with them to reflect upon.

c). Telephone Support – advantages and disadvantages of telephone support emerged, together with views about who should provide it:

1. Advantages

- Telephone support would be essential for people with literacy difficulties.
- The stress of the GP consultation would mean people might forget some of what they are told. Having a telephone back-up would help remedy this.

2. Disadvantages

- Would one be able to get through on the telephone?
- If patients found they could not get through on the telephone, what would happen if this were the only source of information?

- People whose first language is not English said they would not use the phone unless absolutely guaranteed that it would be answered in their language. They would find attempting to explain their language needs very stressful.
- The number should be answered by a person not a recording.

3. Who should provide the telephone support?

- Basing any telephone support on the NHS Direct system aroused mixed feelings. A minority who had had a bad experience of the NHS did not feel confident in telephone support from such a source. Many had not heard of NHS Direct at all.
- Patient groups were mentioned by several participants as a possible provider of this support although one group expressed concern about the fragility of funding for such groups. If funding were subsequently cut, patients would be left with no support.

d) Web-based information - There was a very marked aversion among many of the older people who participated in the project, to using IT. When we took a dummy of the Healthspace website on a lap top to a carers group, there was a noticeable refusal to look at it, touch it or go near it. Others were confident in using the internet but worried about access to it, feeling that it would exacerbate inequities. Accessibility and privacy were key issues raised:

Some Older People and IT

There would be absolutely no question of using computers to access information as they have no understanding of computers whatsoever.
Heston House Care Home

1. Accessibility:

- IT points would have to be accessible for people with disabilities
- Some older people are confident with information technology but some are *'still very unsure and reluctant'*
- People may not be able or willing to have a computer at home
- People on low incomes might not be able to pay to access the internet
- Libraries with free internet access could be used
- For those new to IT, someone should be on hand to help, such as the librarian

Disabled People and IT access

"Accessible IT points- if I cannot see it, I cannot use it (wheelchair access)."
Greenwich Association of Disabled People

2. Privacy

- How would patients using the internet to research information in a public place, have any privacy?
- In internet cafes, it was understood that servers sometimes sold off information about who accessed what and this could be prejudicial

e) Other sources of information: Various suggestions were made about channelling information through existing sources:

- Someone who is trusted by the patient as they already visit them at home e.g district nurse or health visitor
- A peer support group where people already go (such as the Thames Reach Bondway group for homeless people)
- The media such as radio, TV or non sensationalist newspapers
- The BBC in its role of a state funded broadcaster

3.3 CHOOSING WHEN TO BE TREATED

Overall, groups welcomed the ability to choose and book appointments with enthusiasm, particularly those with chronic or multiple conditions who were heavy users of the health service and found clashing appointments were given so they had to refuse one of them. One participant was wary of any consequences of the choices made and wanted to know if there would be a requirement to justify or explain the decision to the NHS.

Older People and Appointment Times

“For people who have arthritis, getting up early for appointments is distressing. They may be awake most of the night worrying about ‘overdoing it’ in the morning.”

Counsel and Care

There was considerable wariness about the process and particularly the need for a password and unique booking reference number. In some groups, particularly the older people to whom we talked this idea generated real alarm, reinforcing their exclusion. Other groups, such as carers of those with dementia, were familiar with having to make important information, such as passwords, accessible to people with dementia and felt this would help, provided the password was given in

writing on the same piece of card as the unique booking reference number, telephone of the hospital, date and time of appointment and how to get there.

3.3.1 The process for patients. Most participants felt that the process as described was accessible and would be beneficial if it speeded the process. Some, however,

Stress of supporting others

“Often older family members live with family and can include both mothers-in-law for example, with the wife taking a lot of responsibility for them.”

Brent Multifaith Forum

felt it was too complicated and would increase their existing dependence, as they would need help with it. Others were very sceptical about this system being grafted onto the existing inadequate systems within the NHS. Concerns were expressed about some aspects of it.

Reality of the NHS

“Valuable time is wasted sitting on phones trying to access hospital departments, options etc. now...”

Action for Sick Children

i) Accessibility

a) Enough time for practicalities- some patients live in more complicated circumstances than others

- Carers who are patients would need time to arrange respite care
- Carers of the patient would need more time to cope as they would have their own needs to cover as well as the patient's needs
- Patients living in sheltered housing will depend on staff to arrange: in-house transport to the hospital, a staff member available to accompany them and information to be disseminated to e.g. the warden, as to where they will be.

Patients who are already stressed

“Patients might feel trapped in the situation and need more time to think about the issue”

Southwark Mind.

- Parents may need to arrange time off work to stay in hospital with a child patient or at home post-operatively
- Parents of child patients in families with more than one child, would have childcare to arrange if they were coming in with the child
- Parents of school age child patients would need time to find out dates and times of school examinations so they could be avoided.
- Language would be a real barrier for those whose first language is not English.

b) Time to reflect on information - The right amount of time for reflection on Choices offered in discussion with friends, relatives or carers (professional and informal) was seen as essential in making Choice a benefit to patients.

- One participant said they would not have time to do research themselves
- Some faith groups would always seek the opinion of their family before reaching their choice
- Where the choice is part of a series of procedures, emotional as well as physical recovery time will be needed between each
- The consensus seemed to be that two weeks was an acceptable time to have to think over choices (subject to urgency of condition and individual circumstances)
- Some patients and families are already very stressed by the trauma of the patient's illness and will need more time.

c) Minimising Stress - Carers, older people living in care homes, families with sick children and those whose first language is not English who responded to this project, all expressed the view that the Choice process would add stress to their already stressed lives but that careful implementation could minimise this.

d) Too much information - There was concern that some people, such as those with a disability, would not be able to cope with all the information at once and would make unwise decisions if they felt pressured

e) The use of the Password - Feelings about this were strong with a number of groups although a minority felt that it would make things easier not to have to repeat name and address each time they had to ring the Call Centre and were reassured by the greater security. Many sought reassurance that the patient could choose the password or suggested a PIN number would be more appropriate and exclusive to the individual. One participant had experienced being confused with another patient of the same name by a hospital. This had caused great confusion and difficulty and taken a very long time to sort out. Passwords would inevitably be shared with family members supporting the patient.

Password

*"I know many older people would be totally unable to access this. Even electronic phone calls are a real problem for potential patients/customers".
Action for Sick Children*

The use of the password was considered to be

- **Discriminatory** to older frail people who might have difficulty with using a password-based system, especially lone people with dementia living in the community
- **A major barrier** to making Choice a benefit to patients
- **Impractical** for patients who are older and frail, or vulnerable
- **Stressful** for those who may have memory difficulties or are on medication which induces them. An added stress for carers in some Faith/BME communities looking after elderly relatives alongside children as well as going to work, being responsible for remembering several passwords and making the phone calls etc for everyone.
- **Aggravating** the anxiety of parents of family members already worried about the patient
- **Worrying** – would it mean your operation would be cancelled if you lost the password, couldn't remember or recite it?
- **Unnecessary** – a finger print would be better. Why can't the GP keep a record of the password – he or she knows all about your medical condition anyway so why can't they know your password? Why can't the NHS number be used?

At the same time the right to privacy and confidentiality was repeatedly raised, in the context of all the various stages in the process.

ii) Appropriate use of GP time

- **Inappropriate use of GP time** - The role of GP in the Choose and Book process was seen as inappropriate as standard practice, because of poor use of GP time
- **Pressure on patient consultation time** – patients did not want their precious seven minutes of consultation wasted on this process
- **Carer involvement** – if a patient with a carer visits the GP alone, the surgery will have to liaise with the carer before booking the appointment, to make sure they are free to support the patient.

Older People and GPs

"Some older people, even if they are confident in other areas of their lives, find visiting their GP intimidating. They will need information to make an informed choice given in a patient and unhurried manner."

Counsel and Care

- **GP as back-up** – in contrast it was also seen as essential to have the GP view as back up and in clinically urgent cases. Some participants felt another GP appointment would always be necessary after the patient had considered options with family and friends.

3.3.2 The Telephone Call Centre

Participants were asked about using the Telephone Call Centre to book their own appointment. Responses are collated in Figure 2.

FIGURE TWO

CHOOSING WHEN TO BE TREATED			
QUESTION: How would you find using the NHS Telephone Call Centre service yourself, to make the booking direct?			
Easy	Fairly Easy	Difficult	Not Answered
4	7	4	5

In one discussion, views were so polarised on the ease of the process that two responses were recorded, one 'easy' and one 'difficult'. Other comments made are collated under various themes.

i) Understanding and trusting the system: Patients would need to have confidence in the system as efficient and responsive; otherwise they would not use it – it would become just another barrier. Information would be needed for patients so they would be ready to use this system, perhaps displayed in the GP's surgery covering:

- What using the Call Centre would involve,
- What would happen if the patient lost their password.
- The status of the Call Centre staff
- The knowledge they would or would not have about patients' circumstances
- Who to complain to if something went wrong
- How to get help using the phone if necessary

Call Centres

“Often Call Centres are difficult or impossible to get through on, also expensive for phone bills.”

Katherine Low Settlement Pensioners' Club

ii) Accessibility is a legal requirement under the Disability Discrimination Act and is also an issue for non-disabled patients:

- Patients who are dependent would have to rely on others feeling 'in the mood' to help, a real barrier to empowerment.
- Someone such as health advocate could call but it would have to be someone who would report back properly and not withhold vital details.
- Having all the information (Call Centre, hospital, advice line, Unique Booking Reference, Password) on a single card to be kept by the phone would be essential so people with mild dementia to use the system
- The same approach would help carers or anyone whose personal circumstances make such processes difficult

- Text phone (Minicom), large button telephones, email and videophone must be built into the user and provider ends of the Call Centre system, so it is accessible for patients with sight, hearing or speech impairments.
- How would people with learning difficulties cope?
- For patients in care homes, staff would end up doing it.
- The GP receptionist should make the phone call for people
- The phone call must be *free*
- People who would have to use a pay phone could not be expected to keep putting money in repeatedly

iii) Other Quality Standards

- Answering times must be fast (unlike the NHS currently all too often)
- Patients must not have to 'hang on' for a long time once they got through
- The option of going back to the GP is essential if telephone use is difficult
- Language needs must be catered for on first contact
- Recorded messages, robotic options etc were disliked.
- The Call Centre should be answered by a human being not a recording
- Call Centre should accept a booking from a relative or friend if the patient has dementia or feels intimidated by the process or use of the password
- There must be no last minute cancellations or unilateral cancellations once booked, by the hospital, as this was very stressful
- Call Centre staff will need to have
 - had adequate training in this technology
 - speak English well
 - be capable of being easily understood by the patient

Telephone Support

"If you speak to an automated line, it can be disconcerting and more long-winded in comparison with talking to a person."
UK Youth Parliament

iv) Practicalities – there were certain practical questions raised by participants which would need to be addressed in the system and publicised in an awareness raising campaign:

- Call Centres should be regionalised so that staff would know the consultants.
- If someone else rang for you, what evidence would they have to produce?
- Could a family member use the password - What authority would they need?
- How close to the appointment could the patient change it?
- Would there be pressure from Call Centre staff not to change it?
- Would you be fined if you wanted to change the appointment?
- Would you be penalised and sent to the 'back of the queue'?
- Would you be subjected to unpleasantness if you wanted to change it?
- Would someone else 'snap up' the appointment while you were trying to make your arrangements, which might be complex?

4. CONCLUSIONS AND RECOMMENDATIONS

4.1 Choosing where to be treated: Whilst all the groups to whom we spoke were supportive of the approach of Choice, there was a strong view that Choice must be part of an overall drive to improve the quality of hospitals, not a substitute for improving the NHS overall. For any patient, finding out that they have an illness which requires surgery or a specialist opinion is stressful. Grappling with information to make a choice of hospital as part of that process can seem daunting, especially for those who are already dependent. People living in care homes, for example, especially those who are frail and confused are entirely dependent on the staff in the care home to make Choice accessible for them. As they are dependent on others for every single aspect of their daily lives, they do not wish to have to 'negotiate' support in Choice, increasing their dependence even more.

Respondents identified a number of problems with information, accessibility and the Choose and Book process. However they frequently suggested solutions and these are incorporated into the recommendations below.

4.1.1 Setting up a Quality Dynamic: It became clear that the exercise of asking patients what information they would like about hospitals to make choices, led to general reflection on aspects of quality in hospitals and of transport. These were very important to certain patients but might not actually apply to any of the hospitals on offer. This indicates that a 'quality dynamic' needs to be set up from Choice so that, through patient and public involvement in the commissioning process, Primary Care Trusts can respond to quality factors which are not to be found in any hospital, to make sure they are there in the future, through the commissioning process. Without this quality dynamic there is a risk that high expectations will be generated by Choice, which are not realistic now and will never become reality, because there is no system to make them so.

Recommendation: Primary Care Trusts should involve patients and carers in their commissioning process in such a way that quality concerns of patients which are not currently met by hospitals can be addressed and monitored through the commissioning process.

4.1.2 Responding to mistrust and lack of confidence in information: our findings show that many respondents indicated their mistrust of information provided to make choices. Because of bad experiences in the NHS in the past, they emphasised that they would want to see the reality of the hospital and talk to someone who had been a patient there, rather than just rely on official information. While an information 'brand' might overcome some of this wariness over time, other ways need to be found to make Choice accessible to patients.

Recommendation: As recommended by participants, patients selected at random from hospitals' lists should be invited to offer personal testimony (by dictation and signature like a Witness statement), using topics from the national patient survey. The feasibility of other suggested solutions should also be explored, namely offering patients the chance to visit hospitals they are contemplating choosing could be

explored and providing a 'Visitors' Book' relating to each hospital on the nhs.uk website.

4.1.3 Identifying the Information required: As can be seen from the findings of this patient and public involvement exercise, there is a core of information which is definable and probably available, and some which is difficult to measure and is largely subjective. Both sets of information would influence the patient experience and this is why both are equally important to them. For example, quality of nursing care was mentioned over and over again as important – yet this is not easily measured.

Recommendation: a template of the information needed by patients, including that needed by socially excluded groups, needs to be developed based on this and other work being done on the issue.

4.1.4 Producing the information required: Findings illustrate that patients may require information which is not readily available. It will be necessary to check what information is already collected to cover some issues. For example, quality of nursing care could be assessed by knowing the hospital's progress scores on Essence of Care.^{xxix} Results of the most recent National Patient Survey would also go some way to indicating quality of nursing care, as it will cover inpatient services from this year.

Recommendation: From August 2004, the National Patient Surveys will include a separate survey of young people. Questions will be asked in both about many of the aspects raised by patients in Taking Soundings and benchmarked reports for all acute Trusts will be available from August this year. After the surveys are published it will be necessary to consider what gaps remain and how they are to be filled. It was suggested, for example, that all hospitals provide booklets on each faith to be made available for staff, patients and visitors.

4.1.5 Making sure information is accessible to those who will need it: For many to whom we spoke, the idea that they would be able to access the internet is insultingly inappropriate, either because they have no familiarity with computers whatsoever, or because they live in such poverty that accessing a computer is out of the question. Others had Basic Skills needs, so making sense of written information would be a problem. On the other hand, we were told that the idea of hanging on a payphone and feeding it with coins while they waited to find out information was not feasible. The advantage of paper based information was seen to be that it can be shared with family and friends and retained for reassurance. Diverse methods of providing information are needed to meet this range of needs.

Recommendation - Telephones: it is absolutely essential that use of telephone helplines is free of charge to the caller.

Recommendation – Internet access: the 6000 UK Online Centres, many located in public libraries provide a valuable resource at low cost or free. All should be free and libraries and Centres should be fully briefed about Choice.

Recommendation – Personal Support: there must be access to a sympathetic advisor who can support disadvantaged patients in interpreting information if necessary, either over the phone or face to face. Participants suggested that

- A peer support group where people already go (such as the Thames Reach Bondway group for homeless people) could be briefed to support patients making choices of hospital.
- All NHS staff should be briefed on Patients Choice so they can signpost patients either to staff with the designated role of supporting patients, or to voluntary sector organisations.

4.1.6 Ensuring consistency in information provision to ensure equality of Choices:

given the range of requirements highlighted in this Report to ensure that information is accessible to all patient groups, it is essential that there is consistency across the country in information content and formats. Furthermore, it is clear that the full range of information provision methods is needed: paper-based, web based and telephone support systems. It is appropriate for Primary Care Trusts to ensure information meets the needs of their communities but it is a waste of time and public money for them all to start from scratch on the issue.

Recommendation – national standards: The template referred to above needs to be tested with patient and user groups and then developed into patient information which meets the ten criteria for laid down by the Consumers Association (see page 7). This information can then be converted into written information, telephone call scripts and web pages, using in each case the resources to do this properly (see Appendix 4)

Recommendation – written information: Sets of A4 Information Sheets should be produced on each hospital, one each for adults, children and people with a learning disability. Familiar symbols can be used to indicate facilities, for example, disability access and parent accommodation. Sheets should be transcribed into Braille and audiotape. Written information must include signposts to sources of the information which is not identified as core within the template, as well as to independent telephone support. There are resources to help produce clear written information but road testing by users should be the final arbiter.

Recommendation - web-based information: this must comply with all the requirements for accessibility specified in this Report. Dummy sites must be road tested by patients with first hand experience of the difficulties described in the Report and modified as appropriate. All websites should include a section on the assistive technology which is available to make them more accessible.

Recommendation – Basic Skills: to help address the Basic Skills needs that will be a barrier for some in assessing the quality of different hospitals, the development of a Learn Direct Basic Skills package covering Choice of hospital, should be explored. There is already such a package on health issues, generally so this could be adapted to cover making a choice of hospital.

4.1.7 Avoiding information overload by developing a 'Patients Choice Information brand': Given the emphasis from participants on authenticated, accessible information, which can make the difference between Choice as empowerment for patients and Choice as extra source of stress, it is important that the information that is provided is consistent, authoritative and comprehensive, but not so comprehensive as to be overwhelming. There is potential for the NHS Patients Choice to develop a 'brand' in reliable, concise information that is, and is seen to be, impartial and objective about all the different choices of provider. This would be a powerful tool for patients amid the plethora of 'information' which is available over the internet and through the media.

Recommendation: the feasibility and cost effectiveness of developing such a brand needs to be explored.

4.2 Choosing when to be treated Although importing the empowerment of booking a holiday on the internet or over the telephone into choosing and booking a hospital appointment is very welcome to most patients, it should not be assumed that the position of a patient, often vulnerable to start with because of their personal circumstances, is in any way similar to someone booking a holiday. As our findings show, for those whose first language is not English, for example, the telephone was seen as a significant barrier. Unless there was a guarantee that the person answering the phone did so in their own language, they would not use a telephone-based service. Some such as those living in a care home would have grave practical difficulties in accessing the telephone and would be dependent on the co-operation of care home staff.

4.2.1 Raising awareness of the Choose and Book process: As suggested by some participants, awareness needs to be raised about this process generally, perhaps through the media such as radio, TV or non sensationalist newspapers or the BBC in its role of a state funded broadcaster. Awareness also needs to be raised within services and providers who currently support patients, as they will need to gear up to help patients in Choose and Book. This will avoid patients who are dependent being required to negotiate the help they need from those upon whom they are already dependent, disadvantaging them in the process.

Recommendation: Advocacy workers, social services staff, care workers, care homes staff, GP practice staff, NHS community services staff such as District Nurses and care co-ordinators in mental health services should be informed of the likely needs of patients arising from Choose and Book, so that they can and do support them.

4.2.2 Responding to mistrust and lack of confidence in the process: Some groups who are regular users of the NHS were sceptical of the ability of the Choose and Book process to be really efficient, because of their experience of the NHS currently. Grafting a new system onto the current inadequacies of the NHS was a concern for them. If hospitals fail to answer the phone efficiently now why should the Telephone Call Centre be any better?

Recommendation: Practice from the commercial and voluntary sector must be adopted. Quality standards covering answering time, provision of information and dealing with special needs of callers, must be incorporated into the Telephone Call Centre system (see Appendix 4). This should not go live until it has been thoroughly tested with a diverse range of users. An on-going user satisfaction monitoring system should be built into the process with regular reporting and review.

4.2.3 Overcoming barriers in the use of the password for socially excluded groups: the use of the password is a major barrier for many of the groups to whom we spoke and will make the process hopelessly impractical for some, such as people with mild dementia or those who get easily confused.

Recommendation: As suggested by participants, the patient could be able to nominate a 'password holder', such as family member or NHS or social services care worker, care home worker or Care co-ordinator. This person would be authorised to ring the Call Centre to make the booking on the patient's behalf, but not for any other purpose. They would not have access to the patient's notes. Such a person could be identified by adding a digit or character to the end of the password. In addition there should be a designated space or box on the print-out onto which the patient could write their password themselves, preserving confidentiality but also keeping the password where they could easily find it.

4.2.4 Overcoming barriers in the use of the Telephone Call Centre: Our findings show that some patients such as those with carers, or who have impaired speech or hearing, or who just do not like the telephone, need to be catered for. Assistive technology is one answer for some but these technologies are not widespread at the moment.

Recommendation: As suggested by participants, a team of 'E-Bookers' commissioned by the PCT could rotate around practices on different days of the week to support patients with information and make bookings for them. Alternatively, the GP receptionist might be given the role of booking within 24 hours of being asked to so - but this would have to be an agreed, designated role not something patients would have to negotiate

People who may already be struggling with their daily lives must not find choice a barrier to care and the stress of accessing care in an unfamiliar way, an aggravation to their circumstances. Respect for the personal difficulties that people face must be built into the Choose and Book system if Choice is not to seem yet another benefit which is for 'the rest of them', and not for all.

^{xxix} *The Essence of Care - patient-focused benchmarking for health care practitioners* Department of Health 2001

Membership of Choose and Book Reference Group

Name	Borough of Residence	Strategic Health Authority
Abdul Khaliq Mian	Waltham Forest	North East London StHA
Alan Hall	Lewisham	South East London StHA
Anthony Fuller	Barking and Dagenham	North East London StHA
Barbara Elster	Redbridge	North East London StHA
Bill Marks	City & Hackney	North East London StHA
Carl Johnson	Ealing	North West London StHA
Cllr Ron French	Bexley	South East London StHA
Elizabeth Duff	Camden	North Central London StHA
Etta Khwaja	Haringey	North Central London StHA
Gerard McMullan	Islington	North Central London StHA
Helena Davis	Barnet	North Central London StHA
Mansukh Raichura	Brent	North West London StHA
Miriam Tarran	Tower Hamlets	North East London StHA
Patrick Condon	Redbridge	North East London StHA
Rose Covell	Bromley	South East London StHA
Chris Baker	Wandsworth	South West London StHA
Sally Brearley	Merton & Sutton	South West London StHA
Stella Ward	Croydon	South West London StHA
Vibert Luthers	Wandsworth	South West London StHA
Cherna Crome	Hounslow	North West London StHA
Graham Trice	Haringey	North Central London StHA
Sue Wales E-Booking Project	Process, Training and PPI Lead,	
Sophie O'Neill LPCP	Project Delivery & Assurance,	
Paul Goodridge Commission for Patient and Public Involvement	Learning and Development Lead	
Elizabeth Manero Health Link	Executive Officer, Health Link	
Delyth Neal Health Link	Project Worker, Health Link	

OUTCOME OF WORKSHOPS WITH CHOOSE AND BOOK REFERENCE GROUP JANUARY 2004

Workshop A - Exploring issues on Patients Choice and e-booking

Workshop B - Use of passwords to protect confidentiality in e-booking

Workshop C – Testing out a draft advert on patients' choice

WORKSHOP A Do you really want to choose?

WHAT WAS ASKED

1. What do you want to choose?
 - a) What treatment to have?
 - b) Where to have your treatment?
 - c) When to have your appointment?
2. When do you want to be able to choose?

FEEDBACK

Overarching issues:

- How much thinking time – what are the limits?
- Need to protect appointment capacity for urgent cases.
- Need advocates to support those needing help in making choices
- Limitations of NHS structure and organisations and choice

Do you want to choose?

General:

- Depends on what is on offer.
- Choice means excess capacity
- Those quick to decide will get in first - less choice for others?
- Requires access to information
- How will a record be made that you have received the right information?
- Worries about competitive advertising and aggressive PR
- Independent sector – following up complications after treatment?

What treatment to have? Yes but

- Would still like advice – where from?
- Important that basic standard of quality is assured to start with otherwise not a real choice.

Where to have treatment? Yes but depends on...

- Choice of doctor as well as hospital?
- Seriousness and type of illness - changes criteria for choice

- Competency of staff
- Specialist competencies found only in particular hospitals

When to have your appointment? Yes if

- At a time convenient to patient
- Made quickly with possibility to change if absolutely necessary.
- Possible problems with receptionists acting as 'gatekeepers' to the service (and to choice?) can be overcome
- Quality control if GP delegates choice discussion to someone else as patient only has 7 minutes for medical discussion.
- Some control on this delegation?

When do you want to be able to choose?

- Can you choose to change hospitals after diagnosis?
- What happens to your 'right' to a second opinion?
- If you must see a series of doctors, must you stay at one hospital?
- Would your treatment be compromised if you did not?

Workshop B - Use of passwords to protect confidentiality in e-booking

WHAT WAS ASKED: What did the group think of the suggestion that passwords be used as well as the NHS Number for patients to access the internet for e-booking?

FEEDBACK

Overarching issue:

- Challenge of translating legal requirements on confidentiality and the Data Protection Act to real situations

Issues:

- Patient should be able to track and see any changes on screen
- There must be a reason given for any changes
- Formats/fonts must be appropriate for those with visual impairment
- Media other than passwords might be more appropriate for people with hearing or speech impairments or learning difficulties.
- Call number identification might be better than password

Workshop C – Testing out a draft advert on patients' choice from the patient perspective.

WHAT WAS ASKED: The Group was invited to comment on a draft newspaper advert about Patient Choice

FEEDBACK

Overarching Issue:

- Note that those reading advert are likely to be ill and anxious.
- Amount of information included in advert is necessarily limited
- Must inspire confidence that
 - this is still NHS (free, accountable, integrated)
 - information will be available to ensure informed choice
 - *not* 'entering the unknown'

The Group divided their response into several sections: Look, style, content, inclusion of information needed to understand the question and of information needed to answer the question.

Look

- Should be same font throughout
- Should be size 14 font or as RNIB recommends
- Hard information should be highlighted
- Use bullet points for clarity
- Some paras have too much text (follow Plain English guidelines)
- Quotes are inappropriate and do not inspire confidence (e.g. getting 'a call out of the blue' - who is this person?)
- Better to remove quotes as give 'naff' tone and add nothing.
- Include a section in main minority languages on getting information in those languages.

Style

- Too much jargon
- Jargon check: 'stand alone', 'treatment centre', 'patient care advisor' (Lay? Clinical? Independent?), 'pre-booked', 'alternative hospitals', 'rolled out', 'eligible', 'fast' (a rush job?!), 'orthopaedics', 'arthrosocopy', 'accredited'.
- Too much of a second hand car salesman 'Arthur Daly' style
- Need more information and less flannel.

Content - Ambiguous or unclear content:

- 'South East' – include postcodes or a map
- Should refer to 'certain operations' rather than list as this over technical and could raise expectations
- Shorter explanation that this will be coming to rest of London
- Missing content:
 - Availability times of telephone info line.
 - Include special short number for ease?

- Availability of text phone and website
- Address to 'you or somebody you care for'
- Make clear NHS identity, free and integrated into the NHS even if non-NHS
- Explain connection with GP and consultant the patient is currently with

Is there the information to understand the question?

- Should include
 - Signposting to other sources of information (e.g on performance and accessibility) or acknowledgement that this will be required
 - Needs to be a logical order
 - 'Eligibility' needs to be explained (loaded term)
 - Do they need to take any further action or just wait – if so how long?

Some What Ifs may occur to the patient and need to be acknowledged and addressed at some stage

- What if the patient develops another condition while waiting?
- What if the patient is incapable of understanding the advert?

Is there enough information to answer the question?

- At the right stage the following information is likely to be required by the patients:
 - Transport before and after
 - ITU available on site
 - Parking cost and availability
 - How much time is given between the choice decision and the operation taking place (practicality for patient of making arrangements)
 - What happens if the patient decides not to take up the choice of an alternative provider – will they be compromised?
 - Who would operate (consultant or lower or trainee?)
 - Follow up – by whom and where?
 - Good written information will be offered

Areas of input of the Choose and Book Reference Group January to July 2004

1. Adverts to go in local press in London to inform the general public of Patients Choice. The group's comments on the proposed adverts led to amendments to the adverts before being published.

2. Transport for Patients Choice – overview of issues

The group was consulted for some guidance on certain areas, by ORH who were commissioned by the Dept of Health to study Transport issues and develop recommendations for changes in transport contracting specifications and the offer of transport.

ORH noted comments from the group on:

Utilising Existing resources to take the place of the phased out offer of 'free' transport for all, originally made available to patients at 'pilot' Choice sites.

Equity and Transparency on what choice of transport should be available and who would authorise it, and what the criteria for deciding who should receive free transport should include.

The Rights/Social Responsibilities of patients when taking up free transport.

Management of Transport Services – the need for standard criteria, health and safety issues, availability for 52 weeks a year.

3. Electronic Booking - Issues on processes

The group discussed and role played 4 Scenarios to test the proposed Electronic Booking processes, covering:

- I. When choosing and booking an appointment with the GP
- II. What information would be required in order to make a choice
- III. When using the call centre to make a booking
- IV. The issues for vulnerable people and other groups

4. Patients Choice Section of the new Health Space Website

The group gave feedback comments on the website screens for E-Booking presented by Stephen Elgar (Information Governance Lead, from NPfIT London). Changes were later made to the screen content and layout taking into account the groups comments.

5. Review of a patient information leaflet on booking for GP surgeries

Views were fed back to the National Team on this. Amendments are to be made to the leaflet accordingly.

Web based Resources to help make Choice accessible

This is just a small sample of the resources available on this topic. They are all web-based on the assumption that NHS providers working on choice will have access to the internet

All Patients

Information

- **The NHS – Toolkit for Producing Patient Information 2003** (www.nhsidentity.nhs.uk/patientinformationtoolkit accessed on 18.7.04) including
 - Templates for providing information about services
 - Guidelines on producing information to different patient groups
- **The Plain English Campaign** – (www.plainenglish.co.uk accessed on 18.7.04) organisation campaigning for Plain English, including
 - Guides on how to write Plain English
 - A-Z of Alternative Words
 - Guide to Medical Information (aimed at the NHS)
- **Hi Quality** – an organisation which produces guidance on reviewing and producing health information (www.hfht.org.uk accessed on 18.7.04) including
 - Guidance on producing high quality information
 - A dummy website on Giving up Smoking to illustrate good and bad practice
- **Aberdeen University: Producing information about health and health care interventions: a practical guide** O'Donnell and Entwistle; Health Services Research Unit University of Aberdeen (www.abdn.ac.uk/hsru accessed on 18.7.04)

Call Centre standards

- **The Telephone Helplines Association** - (www.helplines.org.uk accessed on 18.7.04) provider of specialist information relating to the setting up and running of non-profit helplines, including
 - The THA Quality Standard Workbook
 - Consultancy and Evaluation
 - External assessment and accreditation process
 - The Mental Health Helplines Partnership Project
- **The Call Centre Association** (www.cca.org.uk accessed on 18.7.04) professional body for call and contact centres, including
 - External assessment and accreditation process

- on-line benchmarking
- CCA Standard Framework for Best Practice
- **Cable and Wireless:** large multinational commercial company specializing in telecommunications (www.cw.com/doc/solutions/public_sector accessed on 18.7.04) including:
 - *Improving Quality of Service and Cost Effectiveness of Public-Sector Contact Centres*

Children

Children's Voices – a searchable database from the Commission for Health Improvement containing over 700 individual pieces of feedback from young people about their healthcare, in the form of direct quotes or summaries of typical responses.

Disability Generally

- **The Disability Rights Commission** the statutory body responsible for disability issues (www.drc-gb.org accessed on 18.7.04) including:
 - *The Disability Discrimination Act what it means to you - a guide for service providers*
 - *Good signs for service providers - Improving signs for people with a learning disability*
 - *How to use easy words and pictures - Easy Read guide*
 - *Our Rights our Choices – meeting the information needs of black and minority ethnic disabled people* (with the Commission for Racial Equality in Scotland)
- **AbilityNet**, an organisation which champions IT for people with disability (www.abilitynet.org.uk accessed on 18.7.04) including
 - Web Accessibility Snapshot testing websites for accessibility
 - Fact sheets such as Accessible IT Toolkit, Dyslexia Toolkit and Computing and Learning Disability
- **Enabled London** – a London based disability campaigning group

People with sight impairment

- **Royal National Institute for the Blind** (www.rnib.org.uk accessed on 18.7.04) including
 - Transcription service, to transpose written information into Braille, audio, CD or large print as well as the production of tactile maps and diagrams.
 - *See it Right* Pack on making information accessible to people with impaired sight
 - Web Access consultancy services

People with hearing impairment

- **The Royal National Institute for the Deaf** (www.rnid.org.uk accessed on 18.7.04) including
 - A customised site for NHS professionals with a searchable database of 8000 organisations for deaf and hard of hearing people searchable by organisation name, subject or location
 - *STOP ...before producing information for deaf and hard of hearing people*
 - *Start ... producing information for black and minority ethnic deaf and hard of hearing people*

People with a learning disability

- Transcription service, to transpose written information into Braille, audio, CD or large print as well as the production of tactile maps and diagrams.
- See *it Right Pack* on making information accessible to people with impaired sight
- Web Access consultancy services

Interfaith groups

- **Multifaithnet** - a research, learning, and information tool on world religious traditions and communities <http://www.multifaithnet.org/> accessed on 19.7.04

THE TAKING SOUNDINGS FORM



National Programme for IT,
LondonE-Booking and
Choice Project

**TAKING SOUNDINGS FROM
PATIENTS GROUPS ON
IMPLEMENTING PATIENTS'
CHOICE AND E-BOOKING IN
LONDON**

Response Form

**Thank you for taking the time to complete this Response Form.
There are nine questions plus an evaluation form.**

We will collate responses and evaluations and return them to the NHS London Patient Choice and E-booking team and to our contact in your organisation. We will also send you feedback from the NHS in due course. Our aim is to use this exercise to give patient groups influence over the Patients' Choice and E-booking programme as it is being developed. Thank you for contributing to this aim.

Please return this form by Friday 28th May 2004

- **By post to Health Link at 356 Holloway Rd. London N7 6PA**
- **By fax to 0207 700 8223**
- **By email to office@healthlink.freeserve.co.uk**

Produced by:

Sue Wales, National
Programme for IT, London
Elizabeth Manero,
Health Link

BACKGROUND TO CHOICE – Reforms are taking place across the NHS to give patients more of a say in where and when they are treated.

Choosing where to be treated - From December 2005, it is planned that patients will be offered 4 or 5 choices of where to have treatment when their GP decides they need to have hospital treatment or an operation.

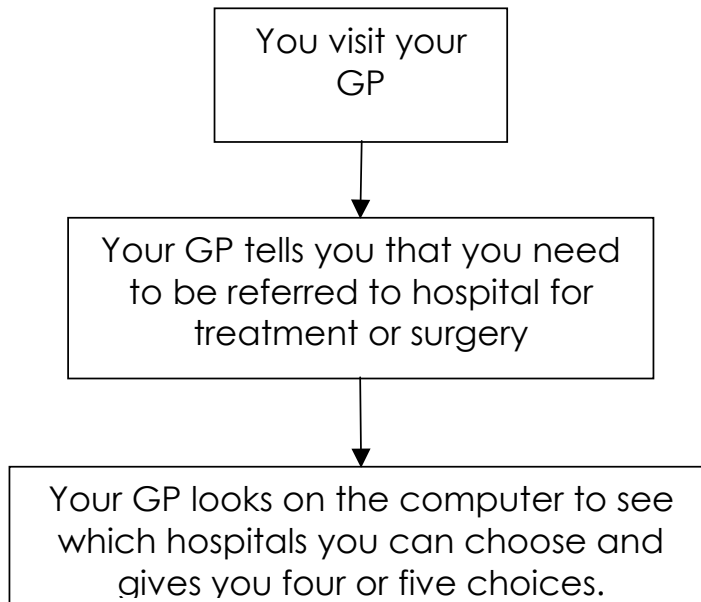
Choosing when to be treated – electronic booking for hospital appointments is also being introduced, starting in certain parts of London this summer. Once the patient has chosen from the list of available hospitals, the GP can book the patient's appointment at the chosen hospital immediately by computer. If the patient wants longer to decide, they will later be able to book direct, by telephone.

WHAT HAPPENS IN PRACTICE - STAGES OF THE PROCESS

The way these reforms are being implemented is being decided on now in the NHS, so we would appreciate your views on how the new systems will work in practice for patients. There are 5 possible stages in the process of how the patient chooses and books where they will have treatment:

1. **The Choice** - You visit the GP who decides that hospital treatment or surgery is required and offers you 4 or 5 choices of hospital.
2. **Immediate Electronic Booking** - You choose a hospital and wish to proceed with a booking right there in the surgery, to a chosen hospital, so the GP makes the booking on his computer.
3. **Consideration by the patient** - You do not wish to choose the hospital immediately, but wish to talk it over with your family or friends or get advice from elsewhere.
4. **Call Centre booking by the patient** - You are ready to make a booking to your chosen hospital, after discussing with others such as your family or friends, so you call the NHS booking Call Centre.
5. **Change of appointment** - You wish to change the appointment you have made.

SECTION 1. CHOOSING WHERE TO BE TREATED



Explanation - there are a number of different places for treatment that the GP may offer the patient, depending on decisions made by the local NHS about what will be offered to patients. The possible choices to be offered to patients, are:

- To go to your local hospital
- To choose a specified hospital outside your borough; outside London; outside the South East
- To choose a specified private hospital paid for by the NHS
- To choose one of the new independent or NHS Diagnostic and Treatment Centre established to provide planned surgery

Topics for Comment

A. What information will you or your carer need, to help you choose which hospital you should to go to for treatment or surgery?

(Please use the box over the page to give us your comments)

RESPONSE BOX

**Information you might need to make a choice of hospital (for example
- cleanliness in a particular hospital or how to get there):**

B. As a patient or carer, how would you like to access the information you need?

Explanation – different patients may prefer to get information to help them choose, from various sources. It is important to know these preferences so the new system can try and accommodate them.

Options currently being considered are as follows. How would you prefer to get the information?

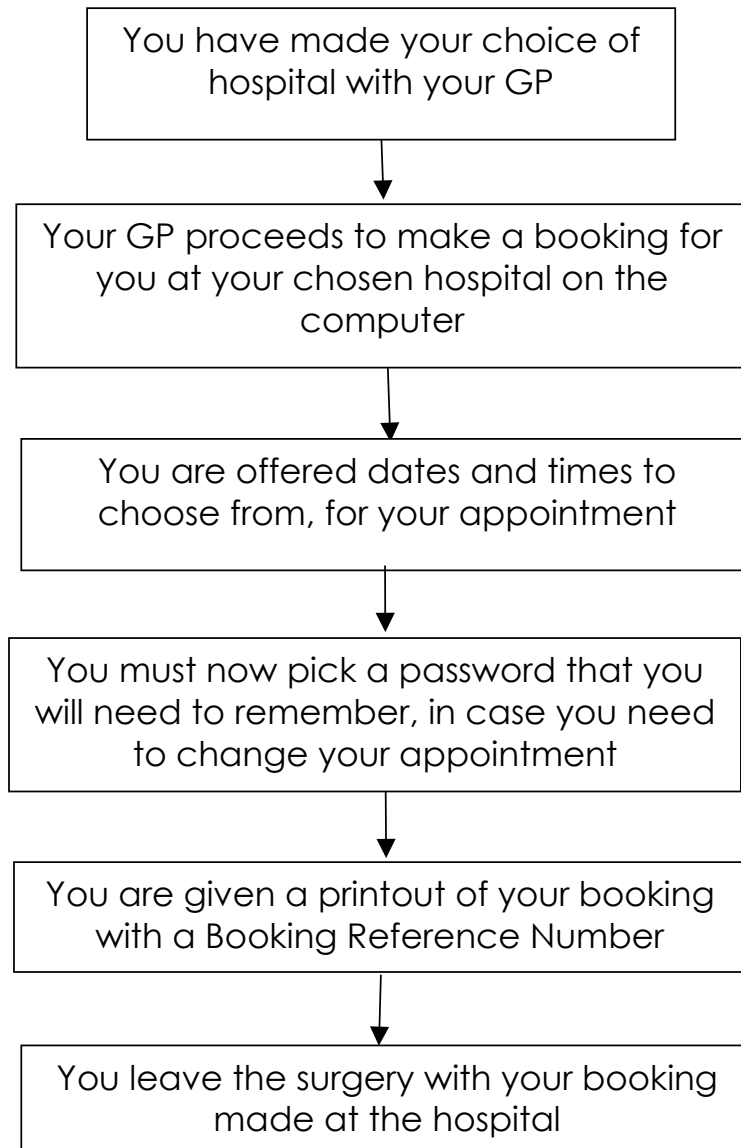
(Please tick more than one option if you wish):

- a) In discussion with your GP
- b) In a written information sheet
- c) Via an independent telephone helpline
- d) Using interactive IT in the GP's surgery
- e) Using interactive IT at home/local library/internet café
- f) Other (please specify below)

RESPONSE BOX

Any other comments on how you would like to access information?

SECTION 2.
IMMEDIATE ELECTRONIC BOOKING - CHOOSING WHEN TO BE TREATED



Explanation – The Electronic Booking System will enable your GP to book you an appointment with the hospital that you choose right there in the surgery, on his or her computer. This means that if you wish to make your decision at that time, you will be able to have the date and time of your appointment in your hand when you leave the GP surgery. Patients may or may not want to use the system in this way.

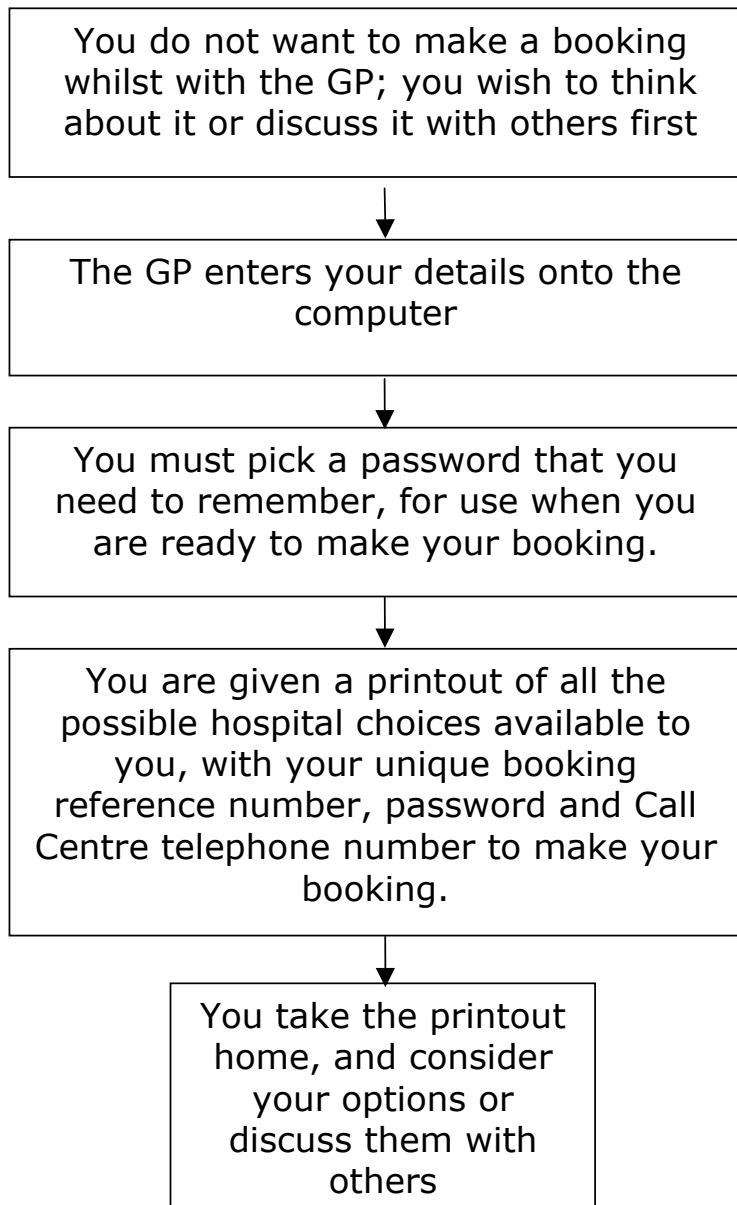
- **As a patient or carer do you have any comments on this process?**

(Please use the box over the page to give us your comments)

RESPONSE BOX

Any comments on this process? (for example on the speed of the process, the use of a password etc)

SECTION 3. CONSIDERATION BY THE PATIENT



Explanation: patients may not wish to decide on a choice of hospital and/or date and time straight away. They may want to have some time to think about it and discuss it with others such as friends or family.

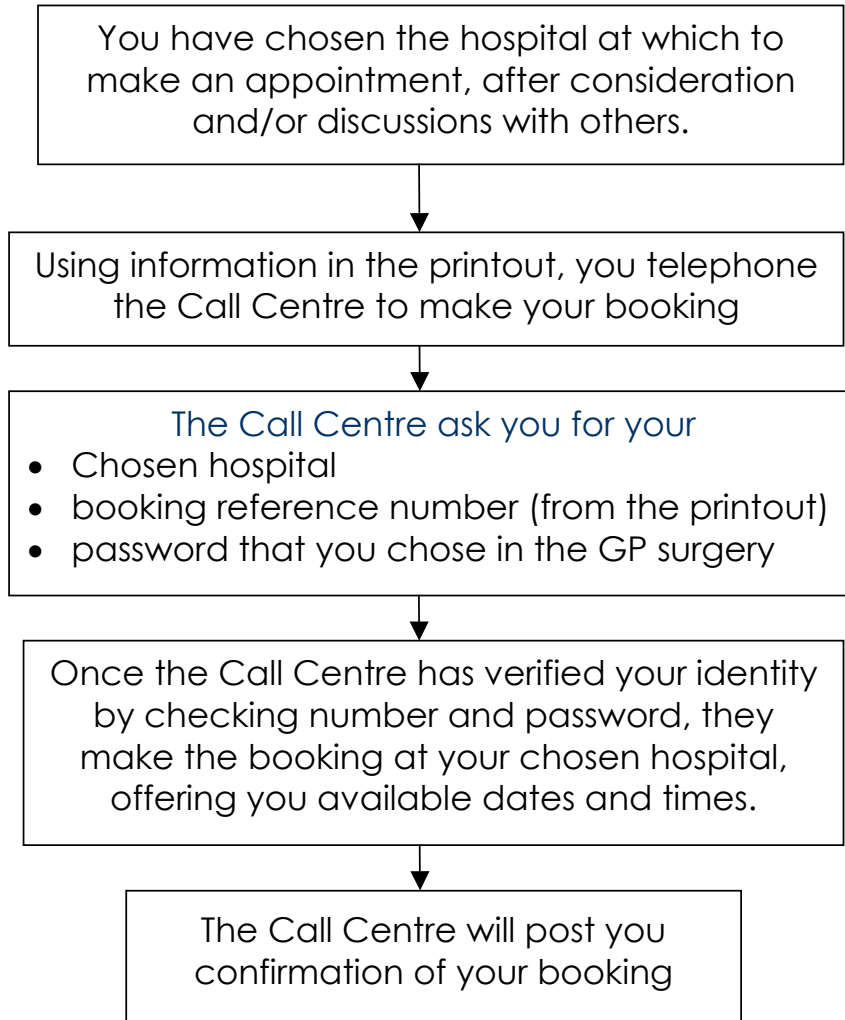
- **Do you have any comments on getting ready to book direct?**

(Please use the box over the page to give us your comments)

RESPONSE BOX

Any comments on the issues for patients and carers of getting ready to book direct (for example how much time they might need)

SECTION 4. DIRECT BOOKING BY THE PATIENT



Explanation: *If you are not ready to make your choice of hospital or pick your treatment date at the end of the consultation with your GP, you will have a chance to consider your choices or discuss them with others. After this, you will be able to book your appointment yourself direct with an NHS telephone Call Centre.*

A.

- **How would you find using the telephone NHS Call Centre booking service yourself, to make the booking direct?**

Easy Fairly Easy Difficult

B.

- **What, if any, might be the difficulties for you in using the telephone Call Centre?
(for example, the use of the telephone or of a password)**

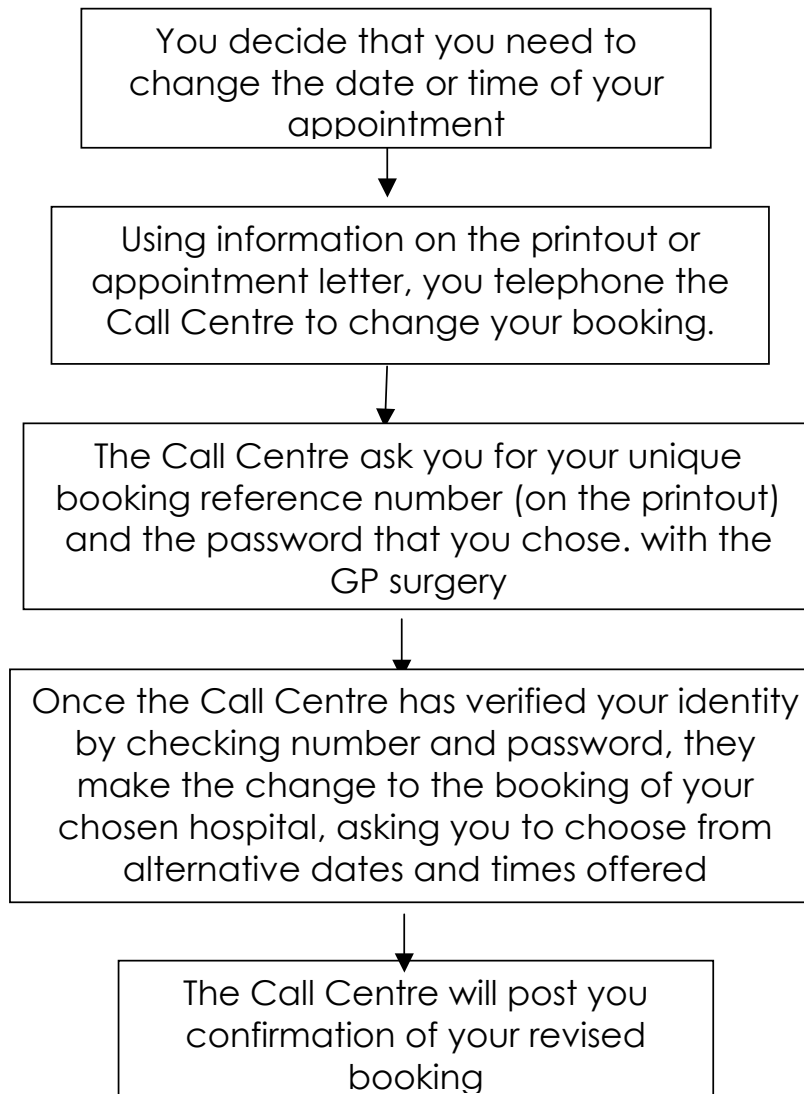
RESPONSE BOX

C.

- **What would help you overcome any difficulties?
(e.g. having someone else to make the telephone call for you)**

RESPONSE BOX

SECTION 5. CHANGE OF APPOINTMENT BY THE PATIENT



Explanation: Sometimes circumstances may change and the patient may need to change the date or time they agreed previously with the NHS for treatment of surgery. Patients will be able to do this by phoning the NHS Call Centre directly.

- **Do you have any comments about this process?**
(Please use the box over the page to give us your comments)
-

RESPONSE BOX

Your comments about this process (for example how much will Call Centre staff know about your type of case)

The end of the Response Form – Thank you for your help

Contact Organisation:

Please Insert the name of your organisation if different:

.....

NHS Patients Choice and Electronic Booking Reforms 'Taking Soundings' Evaluation Form

It will be helpful if one member of your group or organisation could fill in this form and return it to us by 28th May 2004. Thank you.

Please note: We have tried to take an approach with the 'Taking Soundings' process, which fits your groups existing processes. The purpose of this evaluation is to find out how you found this approach and how it can be improved in the future.

Please print the name of your Organisation/group:

Please answer the questions below:

1. Did you have enough background information to enable you to make a response?

Yes No

2. Was the objective of the 'Taking Soundings' process clear?

Yes No

3. Do you have any comments on how this could be improved from your point of view?

4. How would you like us to feedback to you on your responses? By email, post or telephone?

Email By Post By Phone

Please print the contact details for the method by which you wish us to send feedback to you:

Email:

Postal address:

Phone No:

5 Question 5 - Booking Direct												
1. Accessibility												
2. Use of Telephone												

Q	Question and Topic	ASC 1	ASC 2	ASC 3	ASC 4	ASC 5	Az S1	Az S2	ATD	CaF	CC	HH	GDP	IF1	IF2	KLS	Men	MIND	TRB	UKYP
3.	Risk of changed appointment		2									1						1		
4.	Confidentiality																			
5.	Last minute cancellations	2	1					2												
6.	Need for patient to explain/justify decisions?				2															
6 Question 6 - Quantitative (see Report page 35)																				
7 Question 7 - Telephone Call Centre (Code TCC)																				
1.	Accessibility		2				1	2	1			2	1	1	1	1			3	1
2.	Quality of service	1	1				1	1	1			2	2						3	
3.	Someone else to do it for you		1				1	2				3								
4.	Attitude of Staff							2										1		
5.	Confidentiality																			
8 Question 8 - Overcoming barriers (Code D)																				
1.	GP staff role																			
2.	Someone else to do it for you		2											1		1				
3.	Attitude of that person		4																	
4.	A system to inspire confidence																			1
5.	DDA issues																			
9 Question 9 - Changing appointment (Code CA)																				
1.	Accessibility	1																		
2.	System which inspires confidence							1					2							3
3.	Need for support																			
4.	Practical barriers								1											
5.	Pressure not to change								4											
KEY TO ORGANISATION AND GROUP																				

