

**Taking Soundings**  
**Patient and Public Involvement in the**  
**London Patient Choice Project**  
*Testing the views of patients including*  
*'hard to reach' groups*  
**EXECUTIVE SUMMARY**  
*July 2004*



***Strengthening public influence on health***

**356, Holloway Rd.  
London N7 6PA  
0207 700 8135**

[www.health-link.org.uk](http://www.health-link.org.uk)

**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 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 21<sup>st</sup> 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.