The Challenge of Choice – Available but not Accessible?

Spreading public influence on health

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Patients' Choice Reforms: From December 2005, patients needing non-emergency hospital treatment will be offered 4 or 5 choices of where to have that treatment, by their GP. Current plans are that choices will include specified NHS hospitals but may also include a private hospital (paid for by the NHS) or one of the new independent or NHS Diagnostic and Treatment Centres which carry out non-emergency surgery.

Once the patient has chosen from the list of possible hospitals, there are two ways in which the appointment might be booked:

1. GPs will be able to book the appointment for the treatment or operation electronically over the internet, so the patient can choose a date and time immediately from appointments available at the hospital they have chosen.
2. If the patient prefers to take some time to consider their choices, they may book themselves by phoning an NHS telephone Call Centre once they have decided on their choice.

This is an important reform and has the potential to give patients more power. However, the way in which it is implemented will be crucial in ensuring that this power is spread evenly – that old inequalities are not transferred to the new system. The diversity of patients must be understood so that the system is responsive to it. 61% of patients in the London pilot took up the offer of Choice when they had been waiting for six months. Lessons from other NHS reforms are instructive in testing how a new system that has great potential to benefit patients, can benefit not just some but all. Patient Choice is one of the few NHS reforms which requires patients themselves to behave differently, so the patients' perspective is very important.

No Information - no Choice: Seven years ago the concept of choice for women was introduced into maternity care. At that time, the aim was for the NHS to demonstrate a '*systematic programme in place aimed at achieving active partnership with individual patients in their own care, in particular seeking to improve the quantity and quality of information given to enable patient choice about treatment options.*'[1] In response, the Informed Choice Leaflets[2] were produced covering 15 different topics upon which women would be making choices, from place of birth to positions in labour. One set was produced for women and another for professionals, each reciting the available options, evidence that was or was not available and a checklist to help women make decisions. More recent work by MIDIRS includes education tools for professionals on how to support women in the decision-making process. The Leaflets have been peer reviewed by international experts and have the Crystal Mark for Plain English. This is the gold standard for providing information to patients in Choice, converting Choice into Informed Choice.

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[1] *Priorities and Planning Guidance* DEPARTMENT OF HEALTH 1996/1997

[2] www.infochoice.org

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Who will make Choices? Before designing the system for choice it is necessary to look at the characteristics and circumstances of those who will be using it. A short examination of some different patient groups illustrates the diversity which must be matched.

1. **Older People –**

   - Among care homes residents aged 65+, 23% had been in hospital as an inpatient in the past year, 8% as a day patient, and 33% had attended as an outpatient.

   - Residents in private households were less likely than those in care homes to have been in hospital as an inpatient (15%), but more likely to have attended as an outpatient (43%), and did not differ on day patient attendance (10%).[3]

2. **People in lower socio-economic groups** are more likely to have poor health and therefore more likely to use the health service. Comparison between unskilled men and men in professional groups[4], for example, shows

   - Deaths from coronary heart disease are twice as high

   - Deaths from lung cancer are four times as high

3. **People from certain ethnic groups** have higher death rates for some conditions than those born here.

   - Death rates from coronary heart disease are roughly 40% higher among people born in South Asia

These groups will be making Choices so the system must accommodate their needs if it is not to be discriminatory.

Lessons from previous reforms - the implementation of NHS Direct: The National Audit Office evaluation of NHS Direct[5] noted the limitations of the consultation process leading to the establishment of NHS Direct: '*Inevitably there was a trade-off between implementing NHS Direct and extending the consultation process. Members of the consultation groups were generally positive about the opportunities provided to give their views, but there was a consensus that their impact on the direction of development of NHS Direct had been limited.*' There may be a link between this curtailed and possibly ineffectual consultation and the findings of the 2002 subsequent NAO Review on accessibility of the service:

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[3] *The 2000 Health Survey For England: The Health Of Older People (Aged 65+)* DOH 2001

[4] *Securing Good Health for the Whole Population: Population Health Trends* Wanless Dec. 2003

[5] *NHS Direct in England* National Audit Office January 2002sion 2001-2002: E **COMPTROLLR AND A 55 Session 2001-**

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- *'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 that 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'.*

- *'People in social groups D and E are less likely to be aware of NHS Direct - 49 per cent against 61 per cent for the population as a whole.'*

NHS Direct has responded to this Review by various measures to improve accessibility. However, since the advent of the Section 11 duty to consult and involve patients in everything the NHS does[6], the approach taken when it was established is no longer acceptable. If the needs of different patients groups are not covered in the design of the new system, those groups will be excluded from the opportunities that Choice offers.

The Digital Divide: Patients will need information to make Choices between hospitals. It is assumed that some information about different hospitals will be accessed over the internet or via digital TV. However, this would exclude many people. Figures on access to the internet, whether at work, home or elsewhere show that digital access to participation is growing, 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 in some location while 45% use digital TV, but this differs greatly depending on social grade.

Access to the Internet and Digital TV (February 2004 MORI figures)		
Social Class	**Access to internet (from home/work/elsewhere)**	**Use digital TV**
AB	76%	48%
C1	63%	46%
C2	48%	50%
DE	30%	39%

[6] Section 11 Health and Social Care Act 2001

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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.

The latest survey from OFTEL[7] found that although 50% of UK homes have access to the internet at home, this drops to 37% in high deprivation areas and to 27% where annual income is below £17500. Only 25% of over 65s and 14% of over 85s have internet access at home. The majority of NHS users are in this age group. As the 2001 Report[8] for the DFES from the British Educational Communications and Technology Agency stated: *'ICT skills and the ability to access technology facilitate a range of benefits that can be gained as electronically based products and services (including public services, leisure and other cultural resources) become accessible on line (DfEE 2000b). Equality of access, skills and aspirations are essential to ensure that the gap between information rich and poor does not extend to gaps in access to electronically based participatory mechanisms',*

On the basis of the figures given above, roughly half the population are likely to be excluded from using internet based Choice information and booking or processes based on digital TV.

Basic Skills Deficits: Even allowing for differences in accessibility to the internet, the level of skills required to exercise Choice must not be underestimated. Information given in written format may defeat some. There are 7 million adults nationally with literacy and numeracy skills below those expected of an average 11 year old. Levels of literacy and numeracy in some parts of London alone are very poor, depriving patients with such problems of real access to choice. In London almost 23% of 16-60 year olds have poor numeracy and literacy[9]. 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 by the Basic Skills Agency, included

Literacy Tasks	Numeracy tasks
Reading a recipe	Reading a train timetable
Reading a medicine bottle	Choosing the best bank for a loan
Interpreting a newspaper advert	Interpreting graphs
Getting information from Thompson's Directory	Understanding comparative public spending figures

[7] Oftel – Consumers' Use of the Internet October 2003
[8] *The 'Digital Divide': A Discussion Paper* British Educational Communications and Technology Agency April 2001
[9] Basic Skills Agency figures 1996 -1997. Basic skills Survey Results of Adults 2002/2003 awaited **L**

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Some of these tasks are not dissimilar to those required to exercise informed choice about where to have treatment. Choice requires accessible information. For Choice to be for all not just for some, information content and delivery must be inclusively designed round the needs of patients.

Available - but not accessible? Discrimination now has a higher legislative profile through the implementation of the Disability Discrimination Act and the Race Relations (Amendment) Act. A half hearted approach to these issues is not acceptable and would just replace old inequities with new ones. Cultural appropriateness in particular needs to be tested out with faith groups. A female patient from some faiths might be unwilling to discuss a gynaecological procedure on the phone with a male advisor and would be likely to want to know whether female doctors would be available at alternative hospitals. Needing to ask for extra information is itself a barrier. The only way to find out what is important to these groups is to involve them at the very earliest stage in the design of an information template and of a menu of ways in which that information would be offered.

Conclusion – The Wanless Reports[10] noted that access to services may be a factor in the '*social class gradient of mortality*':

'*Lifestyle alone, however, cannot account for the entire gradient in mortality by social class. In addition to the psychosocial factors such as degree of control over one's work, access to or quality of health care treatment may also play a role in the social class gradient in mortality. Cancer survival rates, for example, are worse in more deprived areas for a range of cancers.*

Those in greatest need of public services often have the lowest levels of use and the poorest access to these services. Fewer GPs tend to serve the most disadvantaged communities, the rates of hospital admission for coronary artery bypass grafts and coronary angioplasty are not generally higher in areas with the greatest need (i.e. those in areas with the highest coronary heart disease mortality), and rates of consultation for preventative care are 37 per cent lower in men aged 16 to 24 years from social classes IV and V than for those in social classes I and II. For men aged 25-39 years, preventative care consultation rates are 31 per cent lower for social classes IV and V5.'

It would be ironic if the Choice reform led to similar disparities in access to Choice as exist in access to services, contributing to health inequality instead of alleviating it.

The introduction of the new Section 11 duty to consult and involve patients requires the relationship of the NHS with its community to be completely recast.

[10] *Securing Good Health for the Whole Population: Population Health Trends* Wanless Dec. 2003

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Failure to do this with the Patient Choice reform in particular will lead to new processes with old problems. Measures to reflect the grave inequities in Basic Skills, IT skills and access and participatory disadvantage suffered by some groups, must be built in to the implementation programme of Choice and E-Booking. These principles are legal requirements in the case of ethnic minorities and disabled people. The rate of cervical screening among Bangladeshi women is less than half the average for the rest of the population. This is an example of a service set up to benefit patients but is not accessible to them all. Thorough, early involvement, and responsiveness to what emerges from that involvement, is essential to avoid Patients Choice, like cervical screening, being a service which is in theory available to all but in practice accessible only to some.

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