# health literacy

being able to make the most of health

**by Saranjit Sihota and Linda Lennard**

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# Foreword by John Reid, Secretary of State for Health

The National Health Service (NHS) is improving. This is largely because the public has already made and, if we continue in government, will continue to make, a significant investment in the NHS which will expand capacity and open up choice. On top of this expansion of capacity and increase in choice, we now need to advance on the issue of public health itself, in the face of serious challenges such as obesity, mental health and long-term chronic conditions.

Our white paper on health will be called *Choosing Health* to signify the importance of people making informed choices. We want more people to make more healthy choices. There are few more important ways to do so than by the building of people's knowledge and ability to manage their own health – what can be called their 'health literacy'. The more capable everyone is of understanding the issues that relate to their own health the more they will be able to take responsibility for their own health – whether taking the right course of medication or knowing what a good diet is. The greater the increase in health literacy, the more patients will be able to exercise the choices increasingly open to them in the NHS.

The government is committed to reducing health inequalities, and to achieve this we must widen choice beyond the better-off, beyond those who have traditionally had better knowledge and more information. We therefore need to take action to address the persistent gaps in health literacy that this report identifies, especially among people that are more socially disadvantaged.

The research conducted by the National Consumer Council (NCC) on behalf of the Department of Health is an important contribution to our thinking on the future of the NHS, and the linked issues of choice and equity. The NCC has a unique mandate to reflect the interests of all our public service users, and a strong track record of addressing issues of disadvantage. This report sets out the challenge that lies ahead – ensuring that everyone has the skills and capabilities to benefit from the investment we are making.

Our first major investment was in the capacity of the NHS. This will continue and form the basis for the renewed NHS. We also need to make investment in the capacity of people and patients to make informed choices about their health and the care they receive. An increase in health literacy will increase people's capacity to take more control over their own health and their own lives.

**John Reid**
**Secretary of State for Health**

# Summary and recommendations

The subject of health literacy is vast: it contains innumerable issues and complexities both in understanding its impact on people in varying social, economic and health circumstances, and in defining the appropriate solutions. Therefore this report is a broad first look at the topic, to gauge what we know and what we still need to find out.

## Health literacy

Health literacy is defined as: *the capacity of an individual to obtain, interpret and understand basic health information and services in ways that are health-enhancing* (1).

Health literacy means more than being able to transmit information. It is about developing the skills to be able to acquire and read health information and successfully apply it to one's own situation – whether this means making an appointment to visit a doctor, or adhering to a treatment regime. Improving people's access to health information, and their capacity to use it effectively, is critical to their confidence, and being able to take preventive and prompt action.

The effects of poor health literacy have been documented to include: poor ability to understand healthcare information; difficulties in acting on procedures and instructions; and problems in accessing health services. It has also been related to increased hospitalisation rates, as individuals who present themselves later in the healthcare system obtain less early preventive care (2).

There does not appear to be much direct research into the effects of health literacy in the UK. However, the evidence for a correlation between education and physical health has been found to be robust. Sir Donald Acheson's, *Independent inquiry into inequalities in health* (1998) and the government's cross-cutting review, *Tackling health inequalities* (2002) found that poor educational attainment is a key factor in the cycle of health inequalities. Educational qualifications help to determine an individual's position in the labour market, their level of income and therefore their access to resources. An analysis of over 100 local education authority areas found educational attainment at 15–16 years of age to be strongly associated with coronary heart disease and subsequent infant mortality (3).

Low literacy skills remain a problem for a significant proportion of the population and are clearly associated with socio-economic deprivation, long-standing illness or disability. However, many people underestimate their need for help with literacy. They may also be concerned about the stigma of admitting the need for help (4). These factors present considerable challenges for health services and professionals regarding the communication of healthcare information to patients.

## Information-seeking behaviour

There is a wealth of research to show that patients in general have a desire for information about their health, including: wanting to know what is wrong and why; processes for diagnosis; possible treatments and outcomes; what services are available and whether there are alternatives; and other sources of information. However, little is known about how disadvantaged groups seek and use information, and whether their information needs differ from those of other socio-economic groups because of their likelihood of having poor health, literacy and communication difficulties.

Research is accumulating on people's use of the internet for information on healthcare. Internet access to medical information has the potential to result in a much more active patient and more balanced relationship with health professionals. Lack of access to the internet though, means there is a danger of an 'inverse information law'. People in the greatest need of information about preventable or treatable conditions are the least likely to have access to the information and especially the new technologies (5). Access to the internet at home is lower among older age groups and among people on low incomes (6).

The electronic medical record is likely to affect the way people think about their health. For some patients, access to their own medical records allows them to be more engaged and proactive in managing their care. The evaluation of the Electronic Record Development Implementation Programme (ERDIP) found that patients were more likely to seek information about their health, felt better prepared to ask the 'right' questions in a consultation, and that the doctor listened to them more (7). But studies also reveal that the attitudes of health professionals are often perceived as significant barriers for people to get adequate healthcare information and become more involved in the management of their health. For example, health professionals appearing pressed for time, and not providing the opportunity for patients to ask all the questions they have.

## Shared decision-making

There is a large body of evidence on shared decision-making in health that has gathered over the past ten years. But significant challenges remain in terms of achieving shared decision-making in routine clinical practice.

The decision-making preferences of patients vary, and are like to vary according to the situation faced. Research also shows that there can be a substantial mismatch between the stated preferences of patients for the role they wanted to have in decision-making, and what they felt actually took place in their consultation. Professional attitudes can be a major barrier to patient participation in decision-making.

Many issues need deeper exploration. There is a need to develop a broader-based investigation that goes beyond medically determined studies to include sociological research. This is vital in order to look specifically at differences between groups in decision-making capability and preferences.

Further research is also needed on a number of areas, including how people make decisions, and the capabilities of both patients and professionals, in order to build tools to support decision-making, and systems to ensure continuous improvement as patient and professional competences change.

## Building health literacy

Navigating healthcare systems, engaging in self-care and participating in decision-making, is challenging for many people, and people are especially vulnerable when they are ill, in pain or anxious. Aside from variations in access to health information and in the quality of information, research shows that lay knowledge, beliefs and expectations influence access and use of healthcare services. There are also service-related factors that impact on access and remain to be fully explored and understood. Inevitably these issues affect patients' use and experience of services in different ways, with some more adversely affected than others.

Some measures are in place to assist patients. For instance, patient care advisers (PCAs) have been put in place to help with accessing services as part of choice programmes, there is self-management training to help patients build their capacity for self-care and decision support aids to assist in shared decision-making. However their use is not widespread, and further work is needed to pinpoint problems areas and ensure that the right support is available at the right times to counter inequity.

## Recommendations

### Health literacy
**Recommendation 1:** Quality measures and standards for health literacy should be created. These measures and standards will help to make health literacy an integral part of the healthcare system.

**Recommendation 2:** Health literacy research is needed among health professionals, including allied health professionals – in order to learn more about the challenges of health literacy across the healthcare system.

**Recommendation 3:** Research is needed to measure the impact of poor health literacy on access to healthcare and understand the variation among different groups.

*Information-seeking behaviour*

**Recommendation 4:** A mechanism to monitor the impact of information to support choice and self-care on different population groups is vital. A comprehensive system to collect data in relation to patient characteristics, take up of services and clinical outcome will help to investigate inequity and implement solutions.

**Recommendation 5:** It is crucial that patients have access to material to inform themselves as, when and how they wish, and to use it in discussion with health professionals.

**Recommendation 6:** Research is needed to understand people's information needs across the full range of health services with which they come into contact, including the needs of people who receive care at home and in nursing and residential settings.

**Recommendation 7:** Information should be available in plain language, and should be developed through work with literacy and education providers to create materials that are educative and user-friendly.

**Recommendation 8:** Methods that lessen the burden of paperwork on patients with lower levels of literacy should be developed. This should be done by working with literacy and education providers.

**Recommendation 9:** Bilingual workers or trained interpreters should be available to work with patients who, in addition to having limited English, also possess limited literacy skills.

**Recommendation 10:** The electronic medical record should have the facility to be translated into different languages.

*Shared decision-making*

**Recommendation 11:** Further research is required to understand patient perceptions of what constitutes shared decision-making, and whether the reality of patient consultations and participation match theoretical models. In particular it is important to establish differences among population groups.

**Recommendation 12:** There is a need for better training among health professionals to develop the skills and competencies required for enabling shared decision-making. Patients should be involved in the development of this training.

**Recommendation 13:** Self-advocacy training should be available, especially to individuals with low health literacy, so they can become more empowered by learning what questions to ask.

*Building health literacy*

**Recommendation 14:** To aid the smooth navigation of healthcare systems, support should be available to prevent the risk of patients from being cut off from the system. It is vital to pinpoint problem areas, and for roles such as patient care advisers in the piloting of choice programmes, and support workers in helping access the electronic medical record, and any others deemed necessary, to be properly resourced and supported.

**Recommendation 15:** Information about self-management courses should be made widely available, typically through GP surgeries, health centres, outpatient departments as well community sites such as libraries.

**Recommendation 16:** Self-management courses should be designed to be accessible for patients with low levels of literacy and who speak different languages. They should be developed with literacy and education providers.

**Recommendation 17:** There is a need to expand the research base on decision aids to include:

- impact of decision aids on patients' choice of treatment, satisfaction, health status and persistence with treatment;

- differences among population groups;

- use and efficacy of decision aids in primary care;

- clinicians' perception of decision aids.

# Introduction

Healthcare in England is increasingly moving towards greater choice, shared responsibility between physician and patient for healthcare decisions and increased self-management by individuals. This means the individual or the patient needs to have a variety of skills that will give them the capacity to take on an active role successfully. Therefore, it is important to understand people's inclination, ability and capacity to exert control over their health and care. In particular, to identify variations in skills and capacity to obtain, understand and interpret information as this may well have implications for equity in healthcare and lead to differences in health outcomes (including a potential widening of health inequalities).

This paper was originally commissioned as part of a study to support the Department of Health (DoH) *Consultation on choice, equity and responsiveness* that ran during autumn 2003. It aims to summarise the main research evidence available on health literacy, information-seeking and decision-making behaviour in healthcare. In particular, the focus is on whether there are systematic differences between population groups; that is, whether an inverse information law exists in England where the people most in need are the least likely to be able to access information. There can be both inequalities in access to information in the first place, and also inequalities in people's ability to understand information and take decisions based upon it, in order to influence their health and care.

Given the breadth and depth of the subject matter, it was not possible to carry out a comprehensive and detailed analysis of all available research. However, the paper sets out some key findings and makes recommendations to address the challenges.

This first chapter is concerned with health literacy, the ability to understand information and the extent of the problems resulting from poor literacy skills

Chapter 2 discusses research findings on people's information-seeking behaviour, their needs, barriers experienced in obtaining information, quality of information and the impact of information.

Chapter 3 explores shared decision-making in healthcare, including patient preferences, barriers to participation and the quality of shared decision-making.

Chapter 4 looks at building health literacy and the measures and initiatives currently available, such as patient care advisers to help with accessing choice, self-management programmes and decision-making tools.

# 1. Health literacy

## What is health literacy?

The World Health Organisation states that: *Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.*

In the USA some of the earliest work on health literacy defined it as: *the capacity of an individual to obtain, interpret and understand basic health information and services in ways that are health-enhancing.*

Examples of health literacy include a person having the ability to understand instructions accompanying medication appointment slips, medical education brochures, doctors' directions and consent forms, and the ability to negotiate complex healthcare systems.

Health literacy is not simply the ability to read. Health literacy requires a complex group of reading, listening, analytical and decision-making skills and the ability to apply these skills to health situations. Literacy varies by context and is not necessarily related to years of education or general reading ability. A person who functions adequately at home or work may have marginal or inadequate literacy in a healthcare environment (8).

These days, patients are often faced with complex information and treatment decisions. These involve the need to evaluate information for credibility and quality, analyse relative risks and benefits, calculate dosages, interpret test results or locate health information.

In order to accomplish these tasks, individuals need to be visually literate (able to understand graphs or other visual information), and able to calculate or reason numerically. They need to be computer literate (able to operate a computer), information literate (able to obtain, assess and apply relevant information). And with the development of the internet as a source of health information, they need the ability to search and evaluate websites. Oral language skills are also important, as patients need to be able to articulate their health concerns and describe their symptoms. They also need to be able to ask relevant questions and understand spoken medical advice and treatment directions (9).

However, if patients have poor basic skills in literacy, even information deemed relatively simple to access, understand and use may prove otherwise.

## Effects of poor health literacy

Much of the currently available literature on the topic of health literacy emanates from the USA and Canada. Canada even has a national office designated to address health literacy for the country, while in the USA, many states have initiatives designed to improve health literacy among their populations. According to US research, the existence of literacy problems may not be obvious:

> *Even practitioners who have worked with low-literacy patients for years are often surprised at the poor reading skills of some of their most poised and articulate patients* (10).

Health literacy is receiving attention in the US because of its magnitude. Efforts to quantify it have revealed that an estimated 90 million Americans struggle with low health literacy, and it is said to be costing the healthcare system $73 billion in added expenses (11).

The US Centre for Health Care Strategies has conducted research on the subject, and while the findings are not directly applicable outside the USA, they do provide an indication of the range of possible impacts poor health literacy can have on a healthcare system. The centre's research concluded that people with low health literacy are less likely to:

- understand written and oral information given by health professionals;

- act upon necessary procedures and directions, for example, medication and appointments;

- be able to navigate the health system to obtain necessary services.

People are more likely to:

- receive healthcare services through publicly financed programs;

- incur higher medical costs;

- have poor health status – for example, small-scale surveys showed higher incidence of advanced prostate cancer, and HIV-positive adults more likely to miss treatment doses because of confusion over instructions;

- have higher hospitalisation rates and use of emergency services;

- have less preventive care (12).

*Groups with the highest prevalence of chronic disease and the greatest need for healthcare had the least ability to read and comprehend information needed to function as patients.* (American Medical Association, 1999).

A study of the relationship of literacy to asthma knowledge revealed:

- 31 per cent of asthma patients with reading level of third grade knew they needed to see the physician even when they were not having an asthma attack, compared to:

    - 93 per cent with a high school graduate reading level;

    - 80 per cent with a seventh to eighth grade reading level;

    - 63 per cent with a fourth to sixth grade reading level (13).

In Canada also, strong correlations between literacy and health have been observed by the Movement for Canadian Literacy. Poor literacy was linked to poverty, barriers to healthy child development, increased likelihood of working and living in dangerous environments, and stress.

Other international research evidence (14) on the relationships between learning and health concluded that:

- the evidence for a correlation between education and physical health has been well reviewed and appears to be extremely robust;

- the inter-relationships between learning, health and other variables – such as family background, current family structure, ethnicity, gender, age, socio-economic status, are enormously complex, and change throughout the life course;

- education has a positive impact upon ability to communicate effectively with healthcare professionals and elicit their help, resulting in improved access to health and related services;

- level of education is also associated with closer adherence to medical advice.

## Literacy and health in the UK

In 1999, the Moser Report drew together the available evidence on levels of literacy and numeracy. It found that 20 per cent of adults – or nearly seven million people – had more or less severe problems with basic skills, especially *functional literacy* and *functional numeracy*, described as:

*The ability to read, write and speak in English, and to use mathematics at a level necessary to function at work and in society in general.*

The finding meant that approximately one in five adults had low literacy skills, covering a spectrum of people, from those who cannot read or write at all to those who need to brush up rusty skills (15).

According to the Moser Report, many adults underestimate their need for help: less than five per cent said they had a problem with reading. Many are unaware of poor skills. If they are aware, they may not regard it as a problem. There is also perceived to be a strong stigma to admitting to having a problem.

## Key indicators

### Health

In 2003, a national research study for the Department of Education and Skills found that one in five of those surveyed had a long-standing illness or disability. More than one-third of people with poor or very poor health had literacy skills of Entry Level 3 or below.

The study concluded that those in poor health were particularly likely to lack basic skills. The gaps in literacy performance were not great between those in 'good' and 'very good' health but there were more significant drops in performance at each subsequent step down the health scale. The Moser Report also stated that adults with poor skills were less likely to be in good health.

A total of 5.2 million adults in England could be described as lacking basic literacy (that is, they were at Entry level 3 or below according to National Standards for Literacy and Numeracy). Overall, nearly 18 million adults between 16 to 65 years of age have literacy skills at Level 1 or below. (These statistics are not directly comparable to the Moser Report findings, as the basis for the research differed.)

In the case of numeracy, 53 per cent achieved a lower standard in numeracy than in literacy. Nearly one in two adults, that is 47 per cent were classified at Entry level 3 or below in the numeracy assessment, including one in five (21 per cent) at Entry level 2 or below. This means that 15 million adults in England had Entry level 3 or lower numeracy skills, and that 6.8 million of these were classified at Entry level 2 or below.

The 2003 study reported that low levels of literacy and numeracy were found to be associated with socio-economic deprivation. Adults in more deprived areas, such as the North East of England, performed at a lower level than those in less deprived areas such as the South East. Local authority tenants and those in poor health were particularly likely to lack basic skills (16).

**Entry level 1:** a person can read short texts with repeated language patterns on familiar topics; read signs and symbols and produce limited writing – very short sentences only.

**Entry level 2:** an adult can read short straightforward texts on familiar topics and obtain information from familiar sources (for example, a leaflet, short letter, Yellow Pages). She/he shows some awareness of audience when writing (for example, a short informal letter or note).

**Entry level 3:** an adult reads more accurately and independently and obtains information from everyday sources (for example, popular newspapers). She/he is able to communicate in writing, information and opinions with some adaptation to the intended audience (for example, short formal letter, note or form).

**Level 1:** an adult reads texts of varying lengths on a variety of topics and obtains information from different sources (reports, text books, work manuals). Written communication demonstrates an ability to express ideas and opinions clearly using length, format and style appropriate to audience and purpose (formal letter, memo, brief report, and so on).

**Level 2:** the adult reads from texts of varying complexity accurately and independently, (complex books, text books, reports, training manuals ). She or he writes to communicate information, ideas and opinions clearly and effectively using length, format and style appropriate to purpose, content and audience, (such as a complex letter, essay, report).

## *Age*

Poor health was more common among older respondents: those aged 55 to 65. This group performed at a lower literacy level than other age groups.

A deficiency of both reports cited above is that the research does not appear to cover people aged over 65. Nevertheless, both studies found that literacy problems tend to rise with people aged over 45. However, the Moser Report pointed out that the decline in literacy was associated more with differing life experiences than with ageing. People can lose reading and writing skills if daily life and work make little demand on them. Literacy and numeracy tend to decline during time spent out of employment, although the decline is reduced once a threshold level is reached. The 2003 study found that, generally, age was not a discriminator but there was a tendency for the youngest and oldest respondents to perform at a slightly lower level than other age groups, especially in numeracy.

## *Language*

The Moser Report quoted 1995 research findings that almost half a million people whose first language is not English have little command of the English language. This research identified significant differences between linguistic groups: for instance, Punjabi speakers scored higher than Gujerati speakers (in tasks such as filling in their names and addresses, understanding a simple notice, using a calendar).

The 2003 survey found that language was a barrier to those whose first language was not English. Among those speaking English as their first language, there were only minor differences in skill levels between the various ethnic groups. The low level of basic skills

performance of the wholly English-speaking Black Caribbean population was cited as an exception to this rule.

## *Information and Communications Technology (ICT) literacy*

There are many assumptions and hopes about the internet leading to the emergence of more informed patients who are better able to assess risks and benefits of different treatments. Research on skills and competence in internet searching for health information is building very gradually. Research so far shows that lack of access to the internet and/or poor information literacy has the potential to widen the gap in health and increase social class divisions.

Around half (53 per cent) of all adults surveyed for the 2003 study, had Entry or lower level practical skills (this includes 15 per cent of respondents who had never used a computer)

General awareness of information and communication technology (ICT) terminology was at a higher level than their practical skills. Only one in four (25 per cent) were classified at Entry level or above in the assessment, and half (50 per cent) were classified at Level 2 or above. Almost all of those with Level 1 or above practical skills achieved Level 2 or above in the Awareness assessment. The majority of those who were not currently using computers were classified at Entry level or below in the Awareness assessment.

Men tended to perform at a higher level than women, and those employed in routine or semi-routine occupations were much more likely to have Entry or lower level ICT skills than those employed as managers or professionals. The connection between frequency of use and ability was weakest among those employed in more routine occupations. The majority of frequent users in these occupations had Entry or lower level practical skills.

There are large regional differences in terms of frequency of computer use, home computer ownership and assessment performance. For example, 49 per cent of South East respondents achieved Level 2 or above in the Awareness assessment and Level 1 or above in the Practical assessment, but only 29 per cent did so in Yorkshire/Humber and 31 per cent in the North East. This correlates with regional prosperity and deprivation.

Some individuals show themselves to possess a high level of information literacy, exercising considerable caution and competence when searching and retrieving information, describing techniques (such as comparing different information sources) to ensure that they are not misled. Being aware of their proficiency, they express concern for other less skilled individuals and the difficulty in distinguishing between good and bad information on the internet (17).

Internet use by women wanting information on hormone replacement therapy (HRT) for the relief of menopausal symptoms, showed that although almost half had used the internet to access

health information, the search strategies employed were very unsystematic. There was almost no awareness of whom or what organisation was publishing the information accessed (18).

Overall it is apparent that there is variation in literacy levels and skills amongst population groups. There is also an established link between poor literacy and poor health. Therefore, in order to minimise the risk of cutting off those with poor health literacy even further from the healthcare system, it is vital that the role of literacy and health literacy in the use of healthcare, and their impact on health outcomes is further researched and evaluated. A patient-centred approach that addresses the challenges in navigating the healthcare system and engaging in self-care will enrich understanding of health literacy and how to improve it. This is essential for mitigating the potential for widening health inequalities.

## Recommendations

**Recommendation 1:** Quality measures and standards for health literacy should be created. These measures and standards will help to make health literacy an integral part of the healthcare system.

**Recommendation 2:** Health literacy research is needed among health all professionals, including allied health professionals – in order to learn more about the challenges of health literacy across the healthcare system.

**Recommendation 3:** Research is needed to measure the impact of poor health literacy on access to healthcare and the variation among different groups.

# 2. Information-seeking behaviour

Access to information and the ability to understand and apply it is essential to an individual gaining the capacity to maintain health and manage illness, and exert a measure of control over their life. Information provides knowledge and understanding: it enables people to plan and remain active, as far as possible. This in turn provides a sense of control that is critical to maintaining confidence and self-esteem. It is important therefore, to understand the information needs of patients and the experience of seeking and using information, including whether and how the internet is making a difference.

## Information needs

There is a wealth of research to show that people have an appetite for information about their health concerns. Various research studies have been carried out into what kind of health information people want. From an examination of the literature, patient information needs can be summarised as a need, to:

- understand what is wrong, with clear explanations;

- understand the processes and likely outcomes of tests and treatments;

- gain a realistic idea of the prognosis;

- learn about available services, including options and alternatives;

- engage in self-care;

- identify further information and self-help groups;

- help others around them (family, friends, carers) to understand;

- help them identify other sources of information (19).

However, information materials alone will not solve the problem: there is a need to take a radical look at how professionals are trained in terms of communicating information, and how to share decision-making (see next chapter).

Health professionals frequently underestimate patients' desire for and ability to cope with information. They may lack knowledge themselves about treatment options and effects. Studies in different areas of health concerns and disease show patients have a clear need and desire for more information. For instance, a study on people's use of drug information showed

that people's appetite for information is often greater than doctors believe. It stressed that people have a broad range of information preferences at different times and for different reasons. Interviews with people about drug treatments showed that people respond to information on four essential aspects of a drug: side-effects; what it does and what it is for; dos and don'ts; and how to take it.

Evidence from a number of systematic reviews looking at the information needs of people with cancer have revealed poor communication and inadequate information as the most common complaints. The majority of people prefer to be given as much information as possible – whether good or bad. The information is required for different purposes: to understand the symptoms and/or disease; to learn about available services; and to participate in decisions about treatment options (20).

However, it is important to note that factors affecting patients' take-up of information services are complex. While patients want basic information on diagnosis and treatment, not all want further information at all stages of an illness. Amongst cancer patients it has been found that three over-arching attitudes to illness and coping strategies can limit their desire for and subsequent efforts to obtain information: faith, hope and charity. **Faith:** in their doctor's perceived medical expertise. **Hope:** to carry on with life as normal through silence or avoiding information. **Charity:** to fellow patients, expressed in the recognition that scarce resources – including information and explanations – have to be shared and so limited information is accepted as inevitable (21).

When it comes to learning about the information needs of people in poor health, living in deprived areas, little (if anything) is known. What is known is that their capacity to take on an active patient role is undermined by a combination of factors. Work on coronary heart disease (CHD) in South Yorkshire revealed that lack of knowledge and understanding of ill health had knock-on effects that hampered patient ability to access services. Specifically it showed:

- **Poor knowledge and awareness:** Overall awareness of the causes, treatment and risks of CHD were low. Low visibility of the disease in the community seemed to give rise to low perception of risk. Older people saw themselves more at risk of lung disease; younger people – especially women – thought they were more at risk of cancer.

- **Diagnostic confusion:** This arose when people did not ascribe symptoms to the heart or if they had more prevailing health and social problems. Chronic ill health was often linked to work in heavy industry such as mining; symptoms were attributed to lung problems rather than the heart.

- **Fear:** These were related to the illness and the impact and implications of having heart disease. Poor knowledge and use of drugs combined with denial and self-management as a result of fear meant an unnecessary deterioration in health and quality of life.

The need for much greater public awareness of the nature, causes and risks of CHD is essential to prompt people with acute and chronic cardiac problems to seek help. This finding agrees with other research that has highlighted the influence of lay knowledge, beliefs and expectations on accessing health services. The South Yorkshire CHD study concluded that:

> *Solutions to existing inequalities can start to be identified by listening to the public's perceptions and experiences* (22).

There are also many people who have physical disabilities, learning disabilities and mental health problems. Many of these individuals also have long-term medical conditions. Within the confines of this paper though, it was not possible to carry out extensive research into the available evidence on their information needs and information seeking experience. However, work has been done by voluntary organisations such as SENSE (representing deaf-blind people), the National Autistic Society and no doubt many others to identify the needs of their constituencies regarding access to healthcare information and services.

## Sources of information

Trusted sources of information that have been identified are:

- health professionals as the most popular source for health advice;

- electronic media as becoming important sources;

- non-expert help (friends and family) as always popular (23).

People's information needs extend beyond medical information to knowing how to manage daily living and the stresses imposed by their condition; therefore they require different sources for different information needs. Health professionals, friends and family, people with the same condition and written information are important information sources.

Lay or non-expert sources are generally used to help fit expert information into everyday life, or to fill gaps after consultations if certain questions have been left unanswered. People with the same condition can be a critical source of information, advice and support.

With regard to electronic sources, a body of research is developing on people's use of the internet for information on healthcare. However, little if anything is known about its use by disadvantaged groups. Recent figures show that about 50 per cent of UK homes had internet access in 2003, with access at home being lower among older age groups and among people on low incomes (24).

The value of the internet as a source of information and support is evident in the proliferation of health related electronic support groups. As of April 2004, Yahoo (www.yahoo.com) listed almost 25,000 electronic support groups in its health and wellness section. These groups exist in the form of mailing lists, newsgroups, discussion forums and live chatrooms, and are a mechanism for self-help. People share experiences, ask questions and provide emotional support (25).

Many important questions about the impact of the internet remain to be explored and answered. These include what impact the internet has on the consultation; how it affects patients' participation in decisions; what effect is has on health outcomes, and indeed, what the relevant outcomes are. Further exploration is also required to identify the many different ways and stages the internet is used for information and support, the meanings the internet has for patients and the implications for relationships in healthcare.

## *Patient-held electronic medical records*

Patient-held records are likely to be an important source of information in the future. Research in the USA shows that the most common reasons for patients wanting to read their records is: to see what the doctor has said about them, to be more involved in their healthcare and to better understand their condition. People who consult a variety of sources for healthcare information have been shown to have a keen interest in reading their record:

> *The relationship with internet use is linear. This interest is a logical extension of their involvement in health and represents an opportunity for patients to use the most direct information source available about themselves* (26).

## Access to information

It has been pointed out that lack of access to the internet means that there is a danger of an inverse information law, whereby those with the greatest need for information about preventable or treatable conditions are least likely to have access to new technologies.

Potentially, internet access to medical information can result in a more active patient and a more balanced relationship with the heath professional. Research into the impact of the internet on patients' experience of cancer clearly revealed how the internet was positively transforming their experience. However, it also revealed that the reasons most commonly

given as to why some participants did not use the internet, were the lack of home access and not being familiar with computers (27).

One inner city practice provided free internet access to its primary care population (with varying levels of current access) yet the service failed to attract many users. It concluded that home internet access was preferable, as convenience and privacy are very important to people. Also, while access is necessary, it may not be sufficient for widespread take-up of the internet as a health resource. Patients need to feel confident about their use of the technology, and so motivational factors were also found to be particularly important. In order to use the internet, people needed to view the information as potentially beneficial to their health (28).

## Quality of information

People's desire for, and ability to use, information varies during an illness or a disease process. Numerous findings highlight the importance of individualising information as far as possible to help patients understand their own risk factors and take personal action. The timing of information is crucial. For instance, during the early stages of a disease process, people have difficulty in assimilating health information (29).

Ideal sources of information have been identified as being:

• accurate, up to date, reliable and practically useful;

• accessible in language, format and tone;

• capable of customisation or personalisation;

• available at different levels of detail at different times;

• informative about conditions as well as treatments;

• balanced between a treatment's beneficial and adverse effects;

• available at the time of a consultation and consistent with best advice;

• linked to other reliable and consistent sources of information (30).

However, a survey of research on the information needs of cancer patients cited findings that information materials were found to be lacking in aspects such as: omission of relevant data; failing to give a balanced view of the effectiveness of different treatments; ignoring uncertainties; and rarely promoted a balanced participative approach to decision-making (31).

An exploration of the way in which patient information is constructed and produced, identified three common assumptions:

- that there is an ultimate truth;

- that information is a commodity that can be easily conveyed;

- that health professionals 'have' information that can be 'given' to patients – thereby treating patients as passive consumers of information.

The first assumption has been challenged on the grounds that uncertainty is inevitable and that truth is contestable. The second is criticised on the basis that there is often a lack of consensus among healthcare professionals over `correct' treatment, and healthcare information is often uncertain and contested.

The third assumption is challenged because most information is produced by health professionals for patients but also that involvement by patient groups in the process also leads to the inclusion of particular perspectives and agendas: the assertion is that there is no such thing as value-neutral information (32).

A survey of the readability of patient information produced by hospices and palliative care units in the UK, showed that 64 per cent of the leaflets were readable by only an estimated 40 per cent of the population. This was followed up by research with cancer patients on the use of the leaflets. Most people regarded written information as adjuncts, rather than alternatives to face-to-face discussion with healthcare professionals. There was also some tension between generalised written information and an individual's own experiences of their treatment (33).

With regard to internet information, there is widespread concern about getting online health information from an unreliable source. Professionals and patients differ in their views of patients' ability to tell good information from the bad.

A small study of internet use in the UK showed that, although search techniques were described as sub-optimal, internet users successfully found health information to answer questions in an average of just over five minutes. Participants had varying internet experiences when assessing the credibility of a website. Participants said they primarily looked at the source, design, scientific or official touch, language and ease of use. However, very few noticed and remembered which websites they had retrieved information from, and none checked the 'about us' sections, disclaimers or disclosure statements. The study recommended that further observational studies are needed to design and evaluate educational and technological innovations for guiding consumers to high quality web information (34).

Studies in the US show that patients develop a capability in searching the internet and sifting good information from bad by ensuring that a 'net savvy' person in the person's family does most of the searching. When a new illness is diagnosed, people with internet access reach out

electronically to inform friends and family, and many respond with support, information and advice. Discussions between these private, patient-centred networks serve to help people to sort out good from bad information: a form of online quality control. Where people with a new diagnosis go online to research their condition, it was reported that they frequently seek and receive the help of online communities with the same condition. Experienced online users frequently communicate with online health professionals too (35).

## Barriers to obtaining information

An examination of the literature reveals the following barriers that patients can encounter in obtaining information about their health needs and possible treatments:

- patients having to ask for information, instead of it being offered unsolicited, and being made to feel they have little right to do so;

- health professionals being – or appearing to be – pressed for time, and not providing sufficient opportunity in consultations for patients to ask all the questions they want answered;

- patients not being given enough time in advance to think about what information they need;

- information being provided in ways that are unclear or incomprehensible to individual patients, or presented at a time when patients are unable to fully take it in;

- patients not being given adequate information about possible treatment options, or what these might involve, including potential side-effects.

This is not an exhaustive list as different groups of patients can experience specific barriers. For instance, young people who are disabled or have long-term medical conditions report difficulties in using health professionals, especially hospital doctors, as information sources. Barriers include, information being withheld, exclusion from consultations involving their parents and their doctor; poor rapport with the doctor; an over-concentration on medical matters; shortness of clinic appointments, and the presence of parents at all times (36).

Past experiences and disappointed expectations can also prevent patients from gathering information. This is certainly the case for patients who are from deprived areas. Experiences of negative attitudes of health professionals towards themselves, family or friends result in low expectations and foster barriers in communication and also the access of services.

In the case of minority ethnic groups, communication difficulties inevitably impede the ability of the individuals who do not have English as a first language to obtain information

and knowledge about their health. Aside from the issues raised above, communication problems are often cited as the main reasons for difficulties in diagnosis, treatment and even keeping appointments.

Difficulties in gaining information to exercise self-care have been demonstrated starkly in a study looking at influences on hospital admission for asthma, among South Asian and White adults. It found that while there was no difference between the two groups in socio-economic status, they coped differently. Compared with the White patients, the South Asians who ended up admitted to hospital had a more resigned approach and described less confidence in controlling their asthma, and expressed less confidence in their GP. On the other hand, both South Asian and White patients who had not been admitted to hospital displayed similar confidence in controlling asthma and experimenting with new approaches.

The South Asian patients experienced the greatest difficulty in obtaining the necessary information and support to better manage their asthma. Access to primary care during asthma attacks was prevented by problems such as: doctors providing prescriptions instead of consultations and a lack of nursing support, doctors refusing to visit and telling the patient to arrange admissions themselves. Language problems were seldom raised as an issue, as some GPs spoke Asian languages.  It was concluded that:

> *Difficulties of access probably relate to a range of factors, including organisation, and attitudes within primary care, as well as power issues between general practitioners, staff and patients in areas such as race, class, religion and sex.*

The study clearly illustrates the need for meaningful consultation in primary care, so that questions can be asked and information given. The knowledge is critical to building patients own understanding of preventive treatment and interventions and developing their capacity and confidence in controlling asthma, thereby reducing their risk of hospital admission (37).

## Impact of information

### Personalised information

Research by the Cochrane Collaboration (Cochrane Review) on eight random control trials on the effects of giving records or summaries of consultations to people with cancer showed that, overall, providing a record of the consultation can increase the amount of information recalled by patients, and their satisfaction with the information. Some evidence also suggested that records might encourage participation in subsequent consultations (38).

It has previously been mentioned that patients prefer personalised information rather than general information. Some research on cancer patients has also suggested information should be

linked to electronic patient records. This has implications for the design and implementation of electronic patient records and for patients' use of computer-based resources. The effects of information provision on the anxiety and depression levels of the cancer patients was that 84 per cent showed improvement in anxiety scores. Patients using general information systems seemed more anxious after three months' follow-up. The study suggested that further research is warranted on how information, especially from general sources, affects patient anxiety (39).

## *Patient- held electronic medical record*

A medical centre participating in the Electronic Record Development Implementation Programme (ERDIP) evaluated patient views and attitudes towards electronic medical records held by them on floppy disk.  The evaluation specifically looked at the impact of holding the medical record among patients with diabetes and CHD, and those without either condition. A total of 109 patients participated in the project.

The study revealed that around 40 per cent of patients with CHD reported that holding the medical record encouraged them to seek information about their health. Approximately 60 per cent of patients with diabetes and 20 per cent of patients with CHD, reported monitoring their blood sugar and blood pressure as a result of holding their medical record. Around 21 per cent without diabetes or CHD reported monitoring their weight as a result of holding their record, some also mentioned having reduced their alcohol consumption and increased their exercise.

It is clear that, for some patients, holding their own record allowed them to be more engaged and proactive and in managing their care. There were also signs that people felt better prepared to ask the 'right' questions in a consultation and that patients also felt that the doctor listened to them more.

Another interesting feature was that patients were able to have their record translated into other languages, this proved to be extremely valuable for those who do not have English as a first language. Moreover, it is a facility that gave some patients the confidence and freedom to travel. A patient who was afraid of going to Italy because of her condition, decided to go when the GP at the practice explained that she could have her record translated into Italian and take it with her (40).

## *Internet*

There is much debate on how widespread is the use of the internet and its potential effects on healthcare. There is evidence emerging to show how some people's experience of an illness is being transformed through use of the internet.

Work with cancer patients has shown that the internet was changing patients' experience of cancer and health services in two identifiable ways:

- being able to question their doctor's advice;

- being able to display themselves as competent individuals to friends, family and health professionals, despite serious illness.

The patients looked for information on the internet when they felt they were being given contradictory advice and/or realising that their doctors were not necessarily able to keep up to date with a fast-changing subject. By using the internet, some patients found treatments they preferred and options that they suspected they would not have been given. The internet also enabled them to investigate the expertise and reputation of a hospital and staff, as well as any evidence of 'postcode rationing'.

The patients were acutely aware of the consequences of not doing their own research. A patient who sought a second opinion warned that doctors have neither the time nor expertise to be able to provide all the necessary information. Another individual identified the best treatment for his prostate cancer through his own research and explained that specialist advice is too compartmentalised and incomplete to help decision-making. A young woman with cervical cancer found an experimental treatment via the internet. Although she was aware there were no guarantees it would work, she was keen to protect her fertility and chose to go to another hospital for the treatment. Another pointed out that seeking information can help in planning for the consultation and identify appropriate questions, while lack of planning may result in poor consultations and frustration.

The study concluded that:

> *The ability to access a wide range of disparate information on the internet, coupled with the opportunity to show themselves as technically proficient and discriminating users of this information, enabled respondents to display a modern form of competence and social fitness in the face of serious illness.*

The internet was also valued because it provided privacy as well as 24-hour access.

> *So many people have computers nowadays you haven't actually got to leave your house. It doesn't matter how you're feeling. You don't even have to get dressed; you can just; you know, log on and you can get the information. Which I think is going to do absolutely nothing but help people.* (Man with bowel cancer)

The element of privacy prevented awkwardness or embarrassment and was a feature that was especially important to young men:

*It's so personal because… it's your body, but you have to go somewhere. What better place to go than – well certainly in my circumstances – where I have a computer at home that I can switch on, in total privacy. I don't need to feel that I'm asking dumb questions. I don't need to feel that I have to ask all the right questions first time round.* (Man with testicular cancer)

Another benefit of the internet was that people can search according to their need, for different types, amounts and levels of information.

Many used the internet either directly or via a friend or family member. Internet use was reported most often by men with testicular cancer and least often among the generally older patients with prostate or bowel cancer. Women with breast cancer were among the highest personal users of the internet (41).

It is undoubtedly the case that the need for information exists. Where it is met, patients report less anxiety, with an increased sense of control and an ability to better manage their health and lives. However, the quality of information is variable and there are also problems with access. Variation in access to information is ultimately disempowering: it reduces people's ability to act promptly and engage in self-care, and it erodes self-confidence and access to services impacting negatively on health. The strongest illustration of this is among people living in deprived areas: they exhibit poor knowledge and awareness of disease and risk factors as well as preventive measures, and have late admission to services. This is a challenge that must be addressed if the widening of health inequalities is to be resisted in an environment of choice, self-care and shared decision-making.

## Recommendations

**Recommendation 4:** A mechanism to monitor the impact of information to support choice and self-care on different population groups is vital. A comprehensive system to collect data in relation to patient characteristics, take up of services and clinical outcome will help to investigate inequity and implement solutions.

**Recommendation 5:** It is crucial that patients have access to material to inform themselves as, when and how they wish, and to use it in discussion with health professionals.

**Recommendation 6:** Research is needed to understand people's information needs across the full range of health services with which they come into contact, including the needs of people who receive care at home and in nursing and residential settings.

**Recommendation 7:** Information should be available in plain language, and should be developed through work with literacy and education providers to create materials that are educative and user-friendly.

**Recommendation 8:** Methods that lessen the burden of paperwork for patients with lower levels of literacy should be developed. This should be done by working with literacy and education providers.

**Recommendation 9:** Bilingual workers or trained interpreters should be available to work with patients who in addition to having limited English, also possess limited literacy skills.

**Recommendation 10**: The electronic medical record should have the facility to be translated into different languages.

# 3. Shared decision-making

Involvement in decision-making is a strong determinant of overall patient satisfaction with treatment and outcomes. The importance of patients being better able to understand the range of treatment options and consequences has been demonstrated in studies showing that most patients prefer shared decision-making over strictly professional-based decision-making. Patient participation in healthcare decisions can cover a spectrum ranging from: consulting a patient on a health professional's decision; involving a patient in the decision-making process; shared decision-making; or patient decision-making. The process of decision-making in a health context can be very protracted and fraught with uncertainty. Patients may well wish to have different types of involvement at different times.

## Definition

There are typically three models of decision-making: **traditional**, **informed** and **shared**.

The **traditional** model of decision-making has always been one where the decision is made by the health professional. Interaction between patients and professionals is narrowly viewed as opportunities to reinforce instructions about treatment to obtain compliance and adherence.

In the **informed** model, the exchange is still one-way (from physician to patient) but patients takes decisions on their own. The physician's role limited to that of providing information to enable this to happen. This is described as *'…a consumer-oriented model… that emphasises patient sovereignty and patients' rights to make independent autonomous choices… one where a reasoned choice is made a reasonable individual using relevant information about the advantages and disadvantages of all the possible courses of action, in accordance with the individual's beliefs.'* [26]

**Shared** decision-making is described as straddling *'…the middle ground between medical paternalism and the other extreme where patients are given the sole responsibility for making decisions…'* (42).

The shared decision-making model is about the patient and professional interaction being an opportunity for exchanging information and combining knowledge and expertise so that mutually agreed direction and goals can be established. Shared decision-making allows for patients' values, views and preferences to be made explicit and mediate the professional interpretation of the disease and disability, as well as the selection of treatment and management options. The treatment that best matches the patients' personal values is sought.

However, genuinely engaging in a shared decision-making process hinges on patients understanding their condition and how to manage it. They must also understand the range of treatment options available to them and the pros and cons of each option. It has been suggested that shared decision-making is most important when the following conditions exist:

- when trade-offs exist between near-term and long-term outcomes;

- where there is a small risk of an extremely negative outcome;

- when treatment options appear to have minimal differences;

- where there are dramatic differences in the kinds of outcomes offered by treatment options;

- where there are major differences in the probabilities of complications;

- when a patient is risk-averse;

- when a patients places extreme value on certain outcomes (43).

## Patient preferences

There are significant challenges in achieving shared decision-making in routine clinical practice.

Often health-related decisions can be very difficult. The reasons for this go beyond uncertainty in the scientific evidence and variation in how patients value different outcomes and states of health. Patients' attitudes towards risk also determine their treatment decisions. Risk involves the probability, severity and timing of an adverse outcome. Therefore, some patients may be willing to opt for any treatment that will lessen the frequency of their symptoms, regardless of risk, while others may prefer to trade off greater symptom frequency for less procedural risk (44).

This is one of several reasons why patients' decisions and their behaviours are sometimes at odds with the recommendations of health professionals. A review of research evidence, in the UK and elsewhere, on how patients' preferences about treatment compare with those of clinicians, revealed that patients and health professionals often have different treatment preferences. The differences seemed to vary with the clinical condition, with some evidence that disagreements often existed in the areas of cardiovascular disease, cancer, obstetrics, gynaecology and acute respiratory illness (45).

As well as understanding the research evidence, patients' values, family, culture and religion all have to be taken into account as they play important roles in decisions about health, and in the communication between doctor and patient. Religious and cultural beliefs can have a profound influence on decisions regarding treatment.

However, as discussed in the earlier section, people's information needs vary over the course of a disease process. Likewise, the level of involvement patients' desire in decision-making can also vary:

*Most patients want to see the road map, including alternative routes, even if they don't want to take over the wheel* (46).

A number of recent studies, both here and abroad, show the complexity surrounding decision-making and that the extent of active patient participation in decision-making will inevitably depend on individual preference and on the clinical decision they face.

- In a study of 1012 women with breast cancer, 22 per cent wanted to select their own treatment, 44 per cent wanted to collaborate with their doctors in the decision, and 34 per cent wanted to delegate this responsibility to their doctors. Preferences for active engagement in care vary with patients' backgrounds and the clinical situation (47).

- A Canadian analysis of three qualitative studies of women's decision-making about their healthcare over the life cycle found that participants consistently demonstrated a desire for an active role in the decision-making process. It noted that the decision-making process became more complex and confusing when the information available is conflicting or unclear, lacking adequate evidence, or deeply rooted in personal beliefs and values (48).

- The first systematic survey of the decision-making needs of Canadians indicated that the majority of Canadians have faced complex health decisions, commonly around medical or surgical treatments or birth control. Complex decisions were reported more frequently by women. The strategies used to deal with them included information gathering, values clarification, and seeking support and information from others. The decision to seek institutional care for a family member was the most common single decision next to birth control. It also resulted in the greatest difficulty making a decision (49).

- A study in the US of younger women with breast cancer concluded that this cohort tends to prefer an active partnership to a passive patient role in diagnostic and treatment decision-making. It identified four themes: women's realisation of medical uncertainties; their rejection of physician paternalism; desire for information; and preference for a greater role in decision-making (50).

- A study of the role of preference in decision-making among adult asthma patients in the North West of England, found that most respondents wanted to *contribute to or feel involved* in treatment decision-making but not necessarily to *control it*. The study identified the need for further work on asthma patients' views on the role of nurses in treatment decision-making (51).

## Barriers to shared decision-making

While acknowledging that the decision-making preferences of patients tend to vary, research shows that there can be a substantial mismatch between the stated preferences of patients for

the role they wanted to have in decision-making, and what they felt actually took place in their consultation.

Professional attitudes can be major barrier to patient participation in decision-making. The key challenges faced by doctors have been summarised as follows:

- Practical concerns, including the time needed, and the difficulties in eliciting patients' preferences, exacerbated by limited appropriate information.

- Doctors may not have the appropriate competences, with communication of risk being particularly challenging.

- Patients' preferences may differ from those of their doctor or evidence-based guidelines.

- Some doctors may wish to retain the imbalance of power between themselves and their patients.

- Some patients may be reluctant to share their preferences if they consider their doctor as more powerful and knowledgeable.

- Innovative research and appropriate professional training is needed to find solutions to these problems (52).

Patients' own agendas for consultations with GPs are complex and diverse. Few voice all their agenda during consultation. The most commonly-voiced items concern symptoms and requests for diagnoses and prescriptions.

The most commonly unvoiced items are: worries about possible diagnosis and the future; patients' own ideas about what was wrong; side-effects; not wanting a prescription; and information relating to social factors. The topics that are not raised often resulted in specific problems, including major misunderstandings, unwanted prescriptions, and non-adherence to treatment. It seems therefore that:

> *…in consultations, patients seem only partially present, with only limited autonomy – that is, to make requests but not to suggest solutions* (53).

Other work also suggests that there continues to be a gap between the partnership and negotiation models of practitioner-patient relations and the empirical reality of everyday practice. The experience of mid-life women regarding information sharing on HRT found that expectations and experiences of encounters with healthcare professionals showed serious constraints that inhibited the process of empowerment through information. Many women

who had informed themselves regarding their particular health condition, found that on trying to negotiate with their GP, they had their views and opinions decisively rejected or dismissed. This was especially the case where lay knowledge did not coincide with expert medical knowledge (54).

## Quality of shared decision-making

To narrow the gap between patients' expectations and their experiences, and to help achieve shared decision-making, one of the key experts – and the current editor of the journal *Health Expectations* – has pointed out the need for the following requirements:

- to recast the role of patient, so that they are viewed as active participants;

- for patient support if they are to take on this more active role, including: encouragement, information, education and even training;

- for similar support for health professionals (55).

A sequence of professional competences has also been identified as important features of a consultation aimed at patient involvement in treatment decisions. They are:

- problem definition;

- patient involvement (implicitly or explicitly);

- exploration of ideas, fears and expectations, possible treatments;

- portrayal of options;

- convey equipoise (where there are two or more possible directions, and each could be reasonably chosen);

- identify preferred format and provide tailor-made information;

- check process: understanding of information and reactions;

- acceptance of process and preferred role in decision-making;

- make, discuss or defer decision;

- arrange decision review (56).

Moving towards the goal of shared decision-making also requires attention to the reality of clinical practice. Informing and educating patients about risks, and then eliciting their

preferences is not realistic in a short visit to a general practitioner or even a 45-minute consultation with a specialist. Practical tools based on research are needed to help health professionals and patients learn from one another and work together – see later section on decision aids (57).

Furthermore, a dynamic model of decision-making is one which recognises that the approach adopted during a physician/patient encounter may alter over time, and that the physician/patient interaction is often only one part of a larger process that involves other key participants, such as carers. It is important that health professionals have a flexible approach in order to respect individual differences in patient preferences (58).

A large body of research evidence has steadily accumulated on shared decision-making over the past ten years; some issues warrant deeper exploration. In particular, there is a need to include the development of broader-based investigation that goes beyond medically determined studies. This should include sociological research approaches that look specifically at differences between groups and their skills, preferences and experiences in health decision-making. Research is required on understanding the models of decision-making and instruments, specifying consumer competences, and developing instruments to assess these and interventions to enhance them.

## Recommendations

**Recommendation 11:** Further research is required to understand patient perceptions of what constitutes shared decision-making, and whether the reality of patient consultations and participation match theoretical models. In particular, it is important to establish differences amongst population groups

**Recommendation 12:** There is a need for better training amongst health professionals to develop the skills and competencies required for enabling shared decision-making. Patients should be involved in the development of this training.

**Recommendation 13:** Self-advocacy training should be available, especially to individuals with low health literacy, so that they can become more empowered by learning what questions to ask.

# 4. Building health literacy

People's ability to manage their health, and their experience and use of healthcare services are influenced by an intricate maze of issues. Aside from variations in access to health information and in the quality of information, research shows that lay knowledge, beliefs and expectations influence access and utilisation of healthcare services. There are also service-related factors that impact on access and need to be fully explored and understood. Inevitably, these issues affect patients' use and experience of services in different ways, with some more adversely affected than others. Rigorous research is crucial to elucidate the mechanisms through which health literacy affects health outcomes, service use and behaviours, in order to develop effective strategies for improving health, especially for those with poor health literacy.

Navigating healthcare systems, engaging in self-care and participating in decision-making, is challenging for many, and people are especially vulnerable when they are ill, in pain or anxious about their health. Some measures are in place to assist patients. For instance, in some areas patient care advisers have been put in place to help with accessing services as part of choice programmes, there is self-management training to help patients build their capacity for self-care and decision support aids to assist in shared decision-making. However, much further work is required to pinpoint and ensure that the right support is available at the right times to counter inequity.

## Navigating healthcare

The complexities of healthcare access and use are demonstrable in research, and highlight the need for support to circumvent problems. Research has suggested that there are differences between groups in their willingness or ability to negotiate health systems. Work carried out to compare rates of revascularisation (coronary artery bypass grafting) among South Asian and White patients undergoing angiography, showed that South Asian patients are less likely to receive revascularisation. The differences arose once patients had been placed on waiting lists, but the differences could not be explained by physician bias, nor wholly by socio-economic factors. However, the South Asian patients tended to be younger, male, non-smokers, and more educated than the White patients. This illustrates the need to conduct further research into whether and how the ability or willingness to negotiate systems are causal factors, and the differences between groups (59).

Other investigations into the reasons for South Asian people experiencing greater delays than Europeans in getting specialist management for heart disease found that barriers to services were not related to difficulties in interpretations of symptoms or willingness to seek care. Hindus and Sikhs reported a greater likelihood of seeking immediate care for angina symptoms than Europeans. Therefore, improvements in awareness of heart disease may not decrease delays in receiving care. Capacity to assert control over health and manage a condition can be hindered by service-related factors, and these need to be explored (60).

## Patient care advisers

The role of patient care advisers (PCAs) has been crucial to the piloting of Choice by helping patients to access the choices available. The PCAs are non-clinical professionals who have proved especially important in preventing exclusion from the Choice initiatives of those traditionally deemed disadvantaged and hard to reach. For instance:

- the language line facility has enabled them to communicate with patients whose do not have English as a first language;

- for those who have a physical or sensory impairment, PCAs have been able to make the necessary arrangements for the patient (in advance) at the receiving Trust;

- in some instances, PCAs contacted Social Services on behalf of patients to instigate arrangements for the necessary social care;

- in some cases, the PCAs maintained a relationship with the patient for the entire duration of the care pathway and a further month after surgery.

While a number of areas for improvement have been highlighted, particularly around the gathering and recording of information and obtaining informed consent, it is debateable as to whether without the role of the PCA, some of the hard-to-reach patients would have made use of the choice programmes. The PCAs were not only able to talk to patients about their options but also help make practical arrangements. Therefore:

> *Good quality support of patients from hard-to-reach groups is necessary for them to be able to access the Choice Programme, and the NHS more generally. The careful development of joint decision-making and procedures and the PCA role could be crucial in ensuring that this is achieved* (61).

## Support workers

The value of the PCA role to disadvantaged groups in particular, is akin to that of the support worker/knowledge broker in providing help to access electronic medical records.

Computer literacy is neither universal nor consistent: the employment of a support worker in the medical centre participating in the development of the electronic medical record was found to be essential to help patients with accessing and understanding their record (see page 26). The patients did not express any objections to a non-clinical member of staff seeing their record while teaching them how to access it. The evaluation concluded that:

*Having a 'knowledge broker' or support worker to answer non-clinical queries about the content of the electronic medical record appears to be necessary, although a clinical background may not be essential (62).*

## Nurses

Arguments are often made in favour of nurses assuming the role of patient champions and advocates. The defining attributes (those consistently occurring in the literature) include:

- a therapeutic nurse-patient relationship in which to secure patients' freedom and self-determination;

- promoting and protecting patients' rights to be involved in decision-making and informed consent;

- acting as an intermediary between patients and their families and between them and healthcare providers.

The attributes are described as: valuing; apprising; and interceding.

However, the empirical evidence is sparse as to how the role of advocacy should be interpreted by the nurse in clinical practice. Research questions whether nurses possess the authority to challenge either the medical profession or a bureaucratic healthcare system. Doctors have felt threatened by nurse advocacy because deference to doctors is the unwritten rule of nursing culture. An important point is that this leads patients to perceive nurses as being powerless as representatives.

The concept of nurse advocacy is just as complex and fraught with dilemmas as it is for doctors. Also nurses need to be empowered first if they are to empower their patients. As such it has been asserted that:

*…nurses may have adopted the term advocate to professionalise the art of caring. In this context, advocacy may be serving the best interests of the nurse, rather than that of the patient (63).*

A review of the literature (64) argued that models proposed for the nurse as advocate are indeterminate. This leads to multiple interpretations and consequent lack of clarity in making advocacy operational. While much of the literature focuses on justification for claiming the advocacy role, advocacy is a potentially risky role to adopt, and support systems are inadequate.

## Self-management education

Self-management education is described as teaching patients with chronic and long-term conditions, problem-solving skills, developing their confidence to improve quality of life and working in partnership with healthcare professionals. In September 2001 the government launched *The expert patient – a new approach to chronic disease management for the 21st century*, describing how the NHS in England will help patients have more control over their care. By May 2003 over 2000 people had attended the six-week self-management course. Estimates suggest that up to 19,000 patients can benefit if each Primary Care Trust hosted four pilot courses with between eight to 16 people trained per course.

However, among many professionals the 'expert' patient is synonymous with the demanding and time-consuming patient. A survey carried out in 2003 revealed that 63 per cent of doctors think that, in the long run, better informed patients will require more of their time, a higher proportion than nurses at 48 per cent. Yet studies in the US have shown that a 42-44 per cent reduction in visits to the doctor can be achieved (65).

The benefits of a self-management programme were demonstrated in a randomised controlled study of people with arthritis in the UK. The outcomes for the group who used the programme, included: improvements in health behaviours and symptom management, exercise, relaxation and communication with physicians, as well as decreased pain, depression, fatigue and anxiety. Participants made fewer visits to GPs after attending the programme.

The programme was delivered over six weeks, and provided by trained course leaders. Topics included information about arthritis, self-management principles, exercise, pain management, depression, nutrition, and communication with family and health professionals. It was delivered in community settings, such as church halls and community centres, on a nationwide basis. The participants were predominantly female, with a mean age of around 60 years, with relatively high levels of substantial physical disability (66).

Evaluation of a self-management programme in Australia found that 70 per cent of patients felt better able to cope with life, 75 per cent of GPs felt that their patients were managing their health better, and 50 per cent of the GPs had substantially changed their own management of patients as a result of participating in the programme.

It is suggested that widespread adoption of self-management system will require radical reorganisation of outpatient clinics too, and change in the current practice of most clinicians. However, it is argued that the reduction in outpatient attendance would more than compensate for the initial investment of time to make changes (67).

Evidence from controlled clinical trials in the US concluded that programmes teaching self-management skills are more effective than information-only patient education in improving

clinical outcomes. In some circumstances, self-management education improves outcomes and can reduce costs for arthritis and probably for adult asthma patients. Moreover, initial studies found that bringing together patients with a variety of chronic conditions may improve outcomes and reduce costs (68).

## Decision support

To assist shared decision-making between patient and professionals, especially where tough healthcare choices are faced, practical tools can be very helpful to both parties in arriving at decisions and plans of action.

Canada has made great strides in developing decision aids. It has a Patient Decision Aids research programme residing at the Ottawa Health Research Institute, affiliated with the Ottawa Hospital and the University of Ottawa. It leads an international team that designs and tests decision aids and training programmes for patients and professionals.

### What are decision aids?

Decision aids are described as differing from information *'…mainly in that they contain explicit components to help users clarify their values: the patients' personal values and the utility or importance of the risks and benefits of each alternative are elicited.'*

Decision aids are defined as interventions designed to help people make specific and deliberative choices among options (including the status quo) by providing (at the minimum) information on the options and outcomes relevant to a patient's health. The aid may also have included:  information on the disease or condition; probabilities of outcomes tailored to personal health risk factors; an explicit exercise to clarify values; information on others' opinions; and guidance or coaching in the steps of decision making and communicating with others (69).

Decision aids can be administered by using various media, such as personal computers and CD-ROMs, audio guided workbooks, pamphlets and group presentations.

### Benefits of decision support aids

Over 400 decision aids for patients have been registered and described in an inventory developed by a Cochrane Collaboration review team. A Cochrane review of decision aids to help people make informed decisions about healthcare options concluded that decision aids improve people's knowledge of the options, create realistic expectations of the benefits and harms, reduce difficulty with decision-making, and increase participation in the process (70).

Specifically it was found that the proportion of patients with realistic perceptions of the chances of benefits and harms improved by 40 per cent.  The proportion of patients who are

passive in decision-making was reduced by 30 per cent, and the proportion of people who remain undecided was reduced by 57 per cent.

Research has also found that decision aids can have a strong impact on the use of elective surgical procedures. The rates of use of the most invasive surgical procedures (hysterectomy, mastectomy, prostatectomy, coronary bypass surgery) declined by 23 per cent in favour of more conservative surgical or medical options, without adversely affecting patients' health outcomes, satisfaction or anxiety (71).

A study on models of decision-making pointed out that an important role for decision-aids is their potential for building relationships between the physician and patient. It discussed the process through which exchanging information can enable both to get to know each other, and to see how well they can work together.

Patients come to medical encounters with their own beliefs, values, fears, experiences and information:

> …*patients are not empty vessels. Research into decision aids and other communication methods that focus only on defining the specific message to be conveyed and the most appropriate means of doing so, fail to consider patient factors that might also affect how information is processed and understood* (72).

Decision aids can provide a useful way of displaying and providing patient information about treatment options. However, questions remain about the type of aid to use, the choice of appropriate outcomes to measure, and the effect on communication between patients and professionals. In the US, time pressures are found to be the main barrier to the use of decision aids in practice. Similar barriers are likely to exist in the UK. On the other hand, decision aids could be a way of making better use of the time available by providing a focused and comprehensive framework for discussion (73).

A systematic review of randomised control trials to evaluate the effects of decision aids looked at the range of measures of effectiveness used in those trials. It found that the most commonly used measures were treatment decisions, patient's knowledge and the decision-making process. None of the trials attempted to measure the extent to which the decisions made were consistent with patient's values. It concluded that, within current literature, there was little consensus on what the aims of decision aids should be. It recommended that, if there are choices to be made, evaluations of decision aids should measure the extent that they enable patients to undergo treatments that agree with their values (74).

Decision aids clearly have the ability to enable active patient involvement in decision-making, and have a number of positive benefits. However, research knowledge still needs to be built in

many areas, as there are several unanswered questions. In particular, the impact of decision aids on choice of treatment, satisfaction, health status and persistence with treatment, as well as differences amongst population groups. Also most trials have been done in secondary care and there is little evidence on use in primary care, as well as little data available on clinicians' perception of decision aids and their cost effectiveness.

## Recommendations

**Recommendation 14:** To aid the smooth navigation of healthcare systems, support should be available to prevent the risk of patients from being cut off from the system. It is vital to pinpoint problem areas, and for roles such as patient care advisers in the piloting of choice programmes, and support workers in helping access the electronic medical record, and any others deemed necessary, to be properly resourced and supported.

**Recommendation 15:** Information about self-management courses should be made widely available, typically through GP surgeries, health centres, outpatient departments as well as community sites such as libraries.

**Recommendation 16:** Self-management courses should be designed to be accessible for patients with low levels of literacy, and who speak different languages. They should be developed with literacy and education providers.

**Recommendation 17:** There is a need to expand the research base on decision aids to include:

- impact of decision aids on patients' choice of treatment, satisfaction, health status and persistence with treatment;

- differences among population groups;

- use and efficacy of decision aids in primary care;

- clinicians' perception of decision aids.

# 5. Conclusion

To have the capacity to exercise greater control over their health, people need information, knowledge and understanding. This gives confidence and a will to assert control. People also need to have the skills to be able to identify their information needs, know possible sources or avenues for finding out information, be able to read and understand relevant information, and evaluate their options. The issue is complex, in that other factors have to be taken into account. These include people's psychological and emotional states, especially in terms of the seriousness and stage of their illness and their level of preparedness, which can understandably affect the ability to absorb information.

However, it is clear that information alone is not sufficient, as much depends on the attitudes of health professionals. They are often perceived as significant barriers to people to obtaining information. Patients are less likely to seek information if attempts to do so, or to engage in discussion with health professionals, have been rejected or dismissed.

Studies demonstrate that confidence and trust are particularly undermined among disadvantaged groups by negative experiences of using services. This creates the cycle of a reduced capacity to negotiate systems and achieve quality care, and reduced access to healthcare. It is also known that poor literacy, as well as poor health literacy, is linked to deprivation. Therefore to benefit from choice and engage with better self-care, appropriate measures are needed to build people's capacity to do so.

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