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# Supporting patients to make informed choices in primary care: what works?

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## Executive Summary

- The NHS Next Stage Review promised to expand opportunities for patients to choose their primary care provider. To support choice, patients need accessible, reliable and comparative information about the availability and quality of local services. Some information on local health services is being disseminated through the NHS Choices website but online information will not be suitable for everybody.
- If patients and the public are going to be empowered to use information about quality of primary care then the content should be relevant and designed to suit different needs; the format must be accessible to people with different literacy levels; and different modes of dissemination should be provided to enable everyone to make use of the information.
- Information alone rarely changes behaviour once it has become a habit. An approach that encourages people to think about issues themselves and generate their own arguments for why it might be useful to change GP practice or choose to use health services differently would be more effective.
- Different groups of people value different types of information but the literature suggests that the majority of patients will be interested in both technical and interpersonal aspects of care and they will want 'stories' and 'data' as well as contextual information about their local health service, including the staff.
- Most information about local health services is provided either as written leaflets or through the internet. However, some groups (e.g. low income and ethnic minority groups) are more likely to encounter problems understanding written text and/or accessing the internet. There is a risk that current approaches will reinforce existing patterns of information seeking rather than empower new categories of health care consumer.
- There are various alternative formats to written leaflets that could be used and some of these – such as telephone helplines and digital televisions – are more likely to reach groups that are not well served by current sources of information. Evidence shows that information is far more effective when it is delivered as part of an educational programme.
- Some people will need support to access, make sense of and use information on local services. Without such support, these individuals are unlikely to benefit from opportunities for patient choice in primary care. A number of approaches to providing support are summarised including telephone support by trained advisors, patient decision aids and community based education.

## Introduction

The expansion of patient choice within the NHS has been a major policy goal in recent years. This aims not only to increase the opportunities for people to select providers that best meet their needs, but is also expected to drive up standards as organisations compete to attract and retain patients. While choice of provider was initially developed within the acute sector, arguably it is choice in primary care which may be most important for patients. This is, after all, where an estimated 90% of patient contact takes place (Corrigan, 2005).

The issue of enhancing patients' control and influence over the services they use was central to Lord Darzi's Next Stage Review of the NHS. Foremost this focused on patient choice of general practice, promising that:

*Patients will have greater choice of GP practice and better information to help them choose. We will develop a fairer funding system, ensuring better rewards for GPs who provide responsive, accessible and high quality services (Darzi, 2008: 10).*

In part, this commitment is being pursued through initiatives to create a competitive market within primary care. By encouraging greater plurality it is hoped that patients will have genuine choices to make between a wider range of providers offering different types of service.

But choice is only meaningful if patients know about the options available to them and can compare these effectively. As the government's patient information strategy – *Better information, better choices, better health* – explains:

*High quality information empowers people. With poor information they cannot make effective choices; and without information they have no real choices at all (Department of Health, 2004: 3).*

This means that efforts to foster patient choice in primary care must include the provision of information about the availability and quality of local services. Such information needs to be accessible, reliable, comparative and – above all – must meet all levels of need and ability within the population.

Some information on local health services is now being collated and disseminated through a national website NHS Choices ([www.nhs.uk](http://www.nhs.uk)). The expansion of NHS Choices to include more information on primary care services, particularly general practice, was proposed in the Next Stage Review. However, web based information will not be suitable for everybody. About one third of the population does not have home internet access and some groups (such as older people) are generally less interested in accessing information online.

Moreover, making information available does not mean that it will be used. One of the most consistent findings from research in this area is that information is necessary to empower patients to take a more active role in their health care, but alone it is not sufficient. This raises questions about what additional factors are required to ensure that information is effective in encouraging and helping patients to make informed choices.

This paper summarises the evidence base on patient information and education to address the following issues:

- What types of information do people find empowering?
- Under what circumstances do patients and the public use health information to change their behaviour?
- What types of information do patients and the public need to help them make choices about primary care?
- What skills do people need to access and understand information?
- Which information formats are most effective?
- What support do people need to make informed choices?

The research was originally commissioned by NHS West Midlands, as part of their Investing for Health programme. One of the projects within that programme is currently developing information for West Midlands residents on the quality of local primary care services. More information on that project, and a series of six reports with detailed findings from the HSMC commission, can be found at <http://ifh2.westmidlands.nhs.uk/>.

## What types of information do people find empowering?

The concept of empowerment in health can be applied to people individually and collectively, and can focus on individual self-efficacy or creating and changing organisations and other social institutions. A comprehensive strategy for empowerment would involve both producing information and introducing ways of developing skills that can be utilised by individuals, communities and organisations.

Aujoulat, Hoore and Deccache (2006) found a number of consistent features associated with the concept of empowerment. One of the most important was that there were two dimensions to the process. First, there was an *inter-personal dimension* where empowerment was seen as a product of provider-patient interaction. The process of communication - in which knowledge, values and power were shared - resulted in power being given to the patient. Second, there was an *intra-personal dimension* where empowerment was a process of personal transformation. Power was created within someone or latent power was released from within the self.

The way in which content is presented is part of this empowerment process. Feste and Anderson (1995) identify three methods of empowering patients and these are the use of questions, behavioural language and storytelling (Box 1). Other approaches that appear to facilitate empowerment provide people with the opportunity to go through a number of stages, which have been summarised by Bergsma (2004) and Roter and colleagues (2001) as:

- Analysis, exploration and problem solving
- Relating and reflecting on experience
- Taking thoughtful action.

### Box 1. Three methods to empower patients (Feste and Anderson, 1995)

#### Questions

By using a question-based approach, individuals are encouraged to reflect upon the relevance of issues for their own values and lifestyle. The authors argue that whilst questions move people along their journey through life, answers stop the process of searching. Thus questions encourage people to investigate further and help them to relate information to their own situation.

#### Behavioural language

Some types of language are more likely to lead to changes in behaviour than others. Language that is more likely to encourage people to take action and make choices includes: list, describe, identify, define, decide.

#### Storytelling

This is an approach that facilitates the intra-personal element of empowerment, which requires power to be released from within oneself. Through the use of stories, people find images, values or other material that they can connect with. Individuals within stories can act as role models and help people to understand how they can gain control of their own life.

An important point made in the literature is that although information and education methods can help to empower people, a major element of the content must originate from participants themselves. Feste and Anderson write:

*Tools such as books, video and audiotapes, seminars, discussion/ support groups merely provide the structure for learning. The content of empowerment is the life experience of the person using the tools (1995: 142).*

In sum, literature relating to empowerment from health education places an emphasis on the different stages that an individual needs to go through. These include exploring the relevance of information for their own situation through questions; discussing the implications of the information for different choices they might make through examples such as hearing stories about what happened to people who made different choices; and planning and practicing any actions they might take.

### Under what circumstances do patients and the public use health information to change their behaviour?

A theoretical perspective that seems to be particularly appropriate for the provision of information to enable choice is the Information-Motivation-Behavioural skills (IMB) theory (Munro *et al*, 2007). This can be summarised as:

- Information is the first requisite for behaviour change but not necessarily sufficient in isolation
- The second component, motivation, results from personal attitudes towards changing, perceived social support for the changed behaviour and the person's perception of how other similar people might behave (for example reading stories or TV programmes about why people changed GP and how they benefited)
- The third component focuses on the skills required for the behavioural change and on generating a belief that the behaviour can be achieved (for example, developing skills to understand quality standards and weigh up the advantages and disadvantages of different service features).

A review of behavioural change interventions and low income groups by Michie and colleagues (2008) found clear evidence that people from disadvantaged backgrounds are less successful in achieving behaviour change following participation in formal programmes such as smokers' clinics. The authors concluded that the most common techniques – providing information and facilitating goal-setting – may be helpful for low-income groups, but providing information on its own has little effect on people's knowledge about their own health. Similarly, a review of the evidence on patient information found that people were more likely to understand and recall information when it was delivered in combination with professional support and advice (Coulter and Ellins, 2006).

The UK government's Foresight Programme has produced a report *Tackling obesities* (Maio *et al*, 2007) which provides a useful summary of theory and evidence about changing health related behaviours. The authors focus on habits as 'formidable obstacles' in behaviour change. Habits result in individuals being less motivated to attend to and acquire new information, particularly information that is not consistent with the habit. Habits appear to be less guided by attitudes and intentions than behaviour that requires thought. This means that rational explanations have less power to influence them.

Maio and colleagues' report suggests that if behavioural habits have been established, then information alone will not change the behaviour. Being told to change because the activity is producing a detrimental effect on health will also not be enough, but there is evidence that self-generated arguments are effective. In terms of facilitating choice in primary care, this means not only providing information about the quality of local services, but ensuring that people have the opportunity and skills to reflect on that information and consider how it relates to them personally.

## What types of information do patients and the public need to help them make choices about primary care?

A study by Marshall and colleagues (2006) which explored the information needed by patients to use primary care services in the UK found that current sources of information were not altogether suitable. The authors write:

*...it seems that the public have more modest demands for information about general practice services...than some policy-makers might think (2006: 271).*

So what kinds of information about primary care services do patients want? One answer would be information about those aspects of care they consider important and so this section firstly considers this issue before examining evidence about public reporting of information about service quality in the USA and UK.

### Information needs about local services

Research to create patient survey questionnaires, such as those developed by the Picker Institute and the National Primary Care Research and Development Centre, suggests there are ten broad aspects of primary care that patients consider to be important. These are:

- Access and availability
- Technical/medical care
- Continuity of care
- Interpersonal care/patient centredness/doctor-patient relation
- Involvement in decisions/communication
- Organisation and hotel aspects, physical and environmental needs
- Other professionals – nursing, reception, dentist
- Information and support for patient, family and carers
- Choice and specialist referral
- Outcomes.

These aspects can be subdivided into many detailed areas and some, such as patient-centredness, are very complex. For example, Little and colleagues (2001) identified five components of patient-centred care as:

- Exploring the patients' experience of disease and illness and their expectations for the visit
- Understanding the whole person, their emotions and family context
- Finding common ground, problems, priorities, goals of treatment and roles of doctor and patient
- Health promotion, health enhancement, risk reduction, early detection
- Enhancing the doctor-patient relationship, sharing power, the caring and healing relationship.

There has been a small amount of research carried out to identify which aspects of care are *most* important to patients. Wensing and colleagues (1998) reviewed studies that asked patients to prioritise aspects of general practice care. The aspects of care that were most frequently ranked highly by patients were:

- Humaneness
- Competence/accuracy
- Involvement in decisions
- Time for care
- Availability/accessibility
- Informativeness.

There is also some evidence showing that different aspects of care are valued by different types of patients. Patient characteristics such as age, ethnicity and health status can have an impact on patient preferences, as can the patients' particular situation. For example, increasing age and chronic illness make it more likely that patients will value continuity of care (Pereira and Pearson, 2003). Conversely, patients often prioritise being able to see somebody quickly rather than seeing their regular doctor when they are consulting about a new or minor health problem (Baker *et al*, 2007).

This suggests that a broad range of information may be sought by the public on local primary care services, but that specific information needs may differ from person to person. Some degree of tailoring will be necessary to ensure that patients are able to find the information that they want without having to sift through large volumes of material that they may not consider relevant. This approach is also supported by research, which has consistently shown that patients find tailored materials more relevant, more useful and more informative than generalised leaflets (Jones *et al*, 1999, 2006).

### Impact of information about quality of services

So how do patients and the public react to information about the quality of health services when it is published? Although this type of information has only recently started to be published in the UK, it has been available to the public in the US for some time, so what can be learned from this experience?

In the US, quality information has been published in the form of report cards for over 20 years. Two general types of health care report cards are produced in the US. Some measure outcomes, such as risk-adjusted mortality rates following coronary artery bypass graft surgery. Others measure processes, such as the Centers for Medicare and Medicaid Services' Nursing Home Compare and the National Committee for Quality Assurance Health Plan Employer Data and Information Set (HEDIS).

The evidence suggests that this information has had only a limited impact on the decisions of health service users. Reviews carried out by Marshall and colleagues (2000; 2003; 2004; 2005) found that research demonstrated a number of reasons why health service users did not use information about the quality of health care. These were:

- Difficulty in understanding the information
- Disinterest in the nature of the information available
- Lack of trust in the data
- Problems with timely access to the information
- Lack of choice
- Consumers rating anecdotal evidence from family and friends more highly than empirical evidence.

There are fewer examples of the public reporting of quality of health care in the UK than the US. Hospital mortality rates have been in the public domain since the early 1990s but were not explicitly made available to the public. More recently, public information about quality has increased through the NHS Patient Survey programme and through the work of organisations such as Dr Foster and the Picker Institute. Most of this information is made available on the internet although Dr Foster also published a number of its guides as newspaper supplements.

In focus group research, Magee, Davis and Coulter (2003) found that participants thought that NHS performance should be monitored. But they were quite negative about league tables and found Dr Foster guides to be more user-friendly. Many were suspicious of Department of Health ratings, which in most cases was due to a general distrust of government statistics. Although participants found some of the information useful, they wanted more detail about specific local services rather than generalised comparative information.

Marshall and colleagues (2002) also conducted focus groups to explore this issue. While initial reactions to performance reports were very negative, participants were more positive when the groups were reconvened at a later date and they had had time to develop their views. Service users found league table information useful when the results confirmed their own experience or when other sources of information were not available, such as when they moved to a new area. As a result of their study, the authors later made a number of suggestions about improving the content of quality information (Marshall *et al.*, 2006):

- Information should be tailored to the needs of the public
- Personal experience and similar 'soft' information should be included as well as 'hard' data
- Comparative information was not popular with the public
- Credibility of source was an issue
- Patients wanted contextual information such as NHS structure and staff details as well as information on specific processes of care.

### What skills do people need to access and understand information?

Even when appropriate information is provided, people may not have the skills to understand and use it. This section examines the issue of health literacy and the role of health professionals in facilitating the delivery of information.

#### Health literacy and basic skills

The term 'health literacy' has been used since the 1970s, but it has only gained prominence in the last few years with the growing interest in patient involvement and choice. The most widely used definition of

health literacy is proposed by Kickbusch and colleagues as:

*The ability to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, the health care system, the market place and the political arena (2005: 10)*

People with low health literacy routinely face difficulties in accessing, comprehending and using health information to make appropriate health decisions. Their ability to understand their own health needs and navigate complex health care systems is compromised as a result. The health and financial consequences are profound: numerous studies have shown that people with low health literacy have poorer health, are less likely to adhere to treatments and care plans, make less use of preventive services and more use of unplanned services, and incur substantially higher health care costs (Ishikawa and Yano, 2008).

Most of the research on the extent of low health literacy has been carried out in North America. A major US study reported that almost half of the adult population – some 90 million people – have inadequate health literacy (Ad Hoc Committee on Health Literacy, 1999). In the UK, much more is known about the prevalence of basic skills than health literacy. For example, a national population survey in 2003 found that 16% of adults lacked basic literacy and 47% lacked basic numeracy (Department for Education and Skills, 2003). This equates to 5.2 million and 15 million of 16-65 year olds lacking basic literacy and numeracy skills respectively. The survey showed that people were significantly more likely to be affected by these problems if they were socially deprived, from an ethnic minority background or over the age of 55.

#### Health professionals as 'infomediaries'

The role of health professionals in facilitating the delivery of accessible information is critical for two reasons. First, studies have consistently shown that the majority of the public considers health professionals to be their primary source of information (e.g. Ellins and Coulter, 2005). In the West Midlands, residents taking part in a recent consumer survey were asked where or from whom they were most likely to look for information on local primary care services. The most popular answer was 'directly from my GP', followed by 'leaflets from my GP surgery' (Ipsos MORI, 2008).

Second, as information sources proliferate and information itself becomes more complex, so people will increasingly require some form of help to find the information that they need and make sense of it. This suggests that health professionals will have to develop an information intermediary (or 'infomediary') role: signposting patients to appropriate sources of information, helping them to filter out what is not relevant and supporting them to use that information as part of a decision-making process (Detmer *et al.*, 2003).

However, research indicates that many health professionals are not equipped for this infomediary role and that patients are failing to receive essential health information as a result (Smith, 2000). There may be many reasons for this. Professional attitudes are likely to play a part, with some doctors failing to recognise (and therefore support) the active role that many patients want to play in their own health care. Health professionals may also not be aware of reliable sources of health information to which they can direct their patients. This situation is increasingly likely as the volume of health information proliferates, including a rapid increase in internet based resources. Finally, given that the average length of a primary care consultation is around twelve minutes, there simply may not be sufficient time for professionals to share and talk through information with their patients.

Various tools have been piloted which aim to empower patients to take a more active role during consultations, including cards that act as prompts on appropriate questions to ask the doctor. A series of 'Power Questions' have been developed by the Department of Health to help patients make the most of their GP appointment, focusing specifically on eliciting information about health conditions and treatments (Department of Health, 2007).

A number of studies have evaluated question prompts and have found that these increase patient involvement and question asking – and, consequently, knowledge – without increasing the length of the consultation (Gaston and Mitchell, 2005; Harrington *et al.*, 2004). These benefits are most likely to occur when patients are given specific prompts, rather than generalised information about asking questions. It is of note that strategies which aim to encourage question asking among patients are generally more effective than those which are focused on developing health professionals' communication skills (Coulter and Ellins, 2006).

## Which information formats are most effective?

New ways of delivering information have emerged as a result of innovations in technology but is there any evidence that these new formats are better than more traditional ones? This section examines what is known about the use of different formats.

### Leaflets and other written formats

The majority of patient information is delivered in written format. Traditionally written information has taken the form of leaflets, but increasingly people are accessing this online through health websites or other web based resources. For such information to be beneficial, it must be written at a level and in a way that is comprehensible to consumers – of all reading abilities. The issue of comprehensibility is particularly important in view of the evidence presented earlier about health literacy and basic skills deficits in the adult population. A number of studies have evaluated the readability of patient information leaflets, using tools that assess variables such as word difficulty and sentence length.

These studies make for sobering reading as they consistently report that the vast majority of information leaflets are written at an above average reading ability, making them difficult for many people to understand. For example, Smith and colleagues (1998) reviewed 178 leaflets on asthma that were being provided by general practices in the South of England. They found that only 3% of leaflets were written at a reading grade that would be understood by the majority of the population. A study at two American public hospitals found that 26% of patients could not understand an appointment slip, 42% could not understand directions for taking medicine on an empty stomach and 60% could not understand a standard consent form (Williams *et al*, 1995).

There are two main ways in which the comprehensibility of information materials can be improved. First, the text itself can be written in plain and reader-friendly language, which avoids use of technical terms and jargon. A number of guides to writing in plain English have been produced, and recommendations from the Plain English

Campaign are summarised below (Box 2). Second, there are ways of presenting and organising written information that can make it easier to read. Above all, this includes adequate font size, use of white space to visually break up sections of text, inclusion of supporting illustrations, and organising the information so that it progressively moves from basic to more complex concepts (Horner *et al*, 2000).

For people with low health literacy in particular, it is widely recommended that materials are written in plain language and/or use visual aids to make them easier to understand. Also the use of alternative media has been proposed. There are a growing number of alternatives to the written format, including audio/visual resources, digital TV, telephone helplines, health kiosks and educational approaches.

### Box 2. How to write in plain English

- 1. Keep your sentences short:** clear writing should have an average sentence length of 15 to 20 words
- 2. Use active verbs:** for example say 'you should take the tablet' rather than 'the tablet should be taken'
- 3. Use 'you' and 'we':** try to call the reader 'you' even if they are only one of many people that you are talking about generally
- 4. Use words appropriate for the reader:** say exactly what you mean using words that the reader will understand
- 5. Don't be afraid to give instructions:** these can be the fastest and most direct way of providing information
- 6. Avoid nominalisations:** this is when a verb (eg. provide) is turned into a noun (eg. provision); they can make writing dull and heavy
- 7. Use positive language:** always try to present information in a positive rather than a negative way (eg. use 'do' rather than 'do not')
- 8. Use lists where appropriate:** they are an excellent way of splitting up information

**Source:** Adapted from the Plain English Campaign ([www.plainenglish.co.uk](http://www.plainenglish.co.uk))

### Internet access and use

Population studies have shown a steady increase in use of the internet over recent years. The 2008 national Omnibus survey reported that 65% of British households have internet access (ONS, 2008); this compares to only 46% of households in 2002. However, within this overall trend there are some important demographic variations. The group most likely to have an internet connection in their home – 93% in total – was adults under the age of 70 who had a university degree or higher. By contrast, only 56% of those with no formal educational qualifications reported that they were able to access the internet from home. Similar variations have been reported in relation to use of the internet for health

information seeking. For example, a 2005 national population survey of adults over the age of 45 found that an average of 30% looked for health information on the internet (Ellins and Coulter, 2005). But likelihood of using health websites declined with age; only 19% of respondents aged over 65 had used the internet for this purpose compared to 50% of those aged 45-64. Moreover, use of health websites was significantly higher among more affluent respondents, compared to those from lower socio-economic groups.

The concept of a 'digital divide' has emerged to explain gaps in accessing and understanding the internet which are excluding certain groups from the benefits of new digital technologies (Powell *et al*,

2003). Many of the groups that tend not to use the internet are also least well served by current services and, therefore, have the greatest need for reliable health information. There is a risk that making more information available via the internet will reinforce existing patterns of information seeking – and increase health inequalities – rather than empower new categories of health care consumer.

Cullen (2001) identifies four major barriers that account for the digital divide: physical access; lack of ICT skills and support; attitudinal barriers; and perceived relevance of online content. A key strategy for overcoming the digital divide has been to increase the availability of community-based internet services, for example by locating access points in libraries or other public places. Cullen's analysis suggests that this strategy will have limited effectiveness unless it is accompanied by efforts to: develop consumers' understanding of the internet and their skills to navigate it successfully; address fears and concerns about appropriate internet use; and ensure that online information meets the needs of and is culturally sensitive to those who are accessing it.

### Effectiveness of internet information

There is a substantial body of research assessing the effectiveness of internet health information, including health websites, online educational packages and virtual support groups. Generally, evaluative studies report high levels of user satisfaction with online health information (Coulter and Ellins, 2006). Individuals value being able to gather health resources online, and report that it provides them with access to information that is not routinely provided by health professionals (Nicholas *et al*, 2004). Many evaluations have found that internet information can improve knowledge and understanding of health issues (e.g. Wantland *et al*, 2004), and there is some evidence that it leads to people feeling more empowered to make health-related decisions and more confident during clinical consultations (Eysenbach, 2003).

A further consideration in terms of effectiveness relates to the quality and trustworthiness of health information delivered via the internet. Research by a team based at Sheffield University identified the following four factors as having the strongest influence on consumer trust of health websites (Sillence *et al*, 2006):

- Ease of access to relevant information
- Personalisation and social identification
- Impartiality of advice
- Professional design.

A number of studies have found that consumers generally prefer using the websites of recognisable authoritative sources such as health care organisations or professional groups (Eysenbach and Kohler, 2002; Schwartz *et al*, 2007).

### Audio visual materials

A small number of studies, mostly carried out in the United States, have explored whether pictograms (graphic symbols) improve understanding of health information. For example, Mansoor and Dowse (2003) and Dowse and Ehlers (2005) both explored the impact of pictograms in medicines information for patients with low levels of literacy. The use of visual aids was found not only to improve understanding of the information, but also in one of the studies to lead to significantly higher adherence to prescribed medicines.

A review of the evidence on the role of pictures in health communication confirmed that patients with low literacy skills are most likely to benefit (Houts *et al*, 2006). It found that the impact of pictures on outcomes such as comprehension, recall of information and behavioural change was often positive, but not always. One explanation for this is that an individual's emotional response to pictures affects their impact. In other words, people have to connect with the visual material that is being used. This means using familiar objects and symbols, which may vary across different groups. As with other types of information, a strong message emerges about the limitations of a one-size-fits-all approach.

The findings from 31 studies exploring the use of audiotapes in communicating health information was synthesised by Santo and colleagues (2005). Most of these studies evaluated the effects of audio-taping clinical consultations, rather than the provision of general health or health service information in audio formats. The authors concluded that the evidence for most outcomes – including knowledge, recall of information and anxiety – was mixed, but positive effects were consistently reported in terms of improved capacity to self care and patient satisfaction. Some of the studies found that patients appreciated receiving recorded information, even where this did not lead to an increase in knowledge.

### Digital TV

In 2001, the Department of Health launched four pilot projects to explore the feasibility and effectiveness of health information and advice delivered via digital interactive television (DiTV). The four channels offered a range of resources, combining text and video based delivery. One – DKTV – specifically provided information about local community services, including those related to health and social care. They were evaluated alongside other digital health information platforms being piloted by the Department of Health (Nicholas *et al*, 2004). The evaluation found that, of those with access to the channels, uptake varied from 20% to 37%. Within this overall pattern of use, DiTV appeared to have particularly attracted low income users. The evaluators commented that:

*The evidence from the current research was that DiTV may prove effective at reaching and attracting those social groups that other technologies may not reach (Nicholas et al, 2002: 16).*

Most users – between 67 and 90% – said that they were better informed after using the DiTV service and almost half felt more confident when they next saw their doctor.

### Telephone helplines

One of the downsides of many alternative formats is that they fail to reach people who are least well served by the health system, and therefore most in need of high quality information about how to choose and access services. Technology based approaches can reinforce existing patterns of health information seeking, because they are less accessible and/or appealing to groups such as older people, low income families and people with a lower level of education. But the evidence suggests that telephone helplines are one exception to this.

A national population survey of adults aged 45 and above asked about use of different sources of health information (Ellins and Coulter, 2005). It found that 50% of affluent respondents were likely or very likely to look for information on health websites, compared to only 22% of respondents from lower social grades. But the opposite trend was found for telephone helplines such as NHS Direct. Reported likelihood of calling a telephone helpline was 29% among affluent

respondents, and 40% among respondents from lower social grades. Moreover, similar levels of interest in telephone helplines were expressed by respondents of all age groups.

### Kiosks

There is growing interest in providing health information to consumers via touch screen kiosks, which can be sited in public areas such as doctor's surgery waiting rooms, pharmacies or libraries. Evaluations have generally shown that patients find kiosks easy to operate and understand (Nicholas *et al*, 2001). This might explain why they tend to reach a broader cross-section of the population than alternatives such as the internet. While older people are more likely to use a kiosk than access information online, use of both technologies among this group is very low. One study found that 8% and 1% of older people looked for health information using a kiosk and the internet respectively (Nicholas *et al*, 2003). Its authors also noted that kiosk use was significantly lower among 55-74 year olds, compared to the general population overall.

A review of the literature on kiosks found that this yielded a fairly consistent set of findings (Jones, 2008). An initial burst of enthusiasm for kiosks tends to drop off fairly quickly. To some extent, this trend can be stemmed if patients are encouraged to use kiosks and shown how to do so. Careful thought needs to be put into how kiosks are integrated into the health care setting and patient experience, otherwise they tend to be neglected. They are far more likely to be used if they are multi-purpose, suggesting that patients respond to kiosks which offer a 'one stop shop' for different activities, only one of which is delivering health information.

### Educational approaches

Information can also be provided as part of a broader package, where the focus is explicitly on educating the user. This approach can be delivered in a variety of different ways, including written manuals, telephone support and group based sessions. In some cases, there is a focus on the development of specific skills as well as improving participants' knowledge of health-related issues.

A clear message emerges from the literature about the limited impact of information-only educational approaches, such as leaflets or manuals. Providing written information may help patients feel more informed, particularly

if the materials are tailored to the user in some way, but rarely do they lead to behavioural change. For example, a Cochrane Systematic Review of information-only asthma education programmes found no evidence that these influenced patients' skills, behaviours or attitudes (Gibson *et al*, 2002).

Embedding information into an educational programme is significantly more effective. Studies show that a whole range of outcomes – such as knowledge, behavioural change and use of health services – can be improved with even relatively short educational interventions (Coulter and Ellins, 2007). However, the issue here is whether these effects are sustained once the programme has finished. Most evaluations measure only short term outcomes; those that have included longer term follow up tend to show that benefits decrease over time. This suggests that any initial educational programme needs to be supplemented by regular opportunities to reinforce and refresh participants' new knowledge and skills.

The benefits of professionally-led (clinic based) and lay-led (community based) education have been documented, and there is evidence that some people may respond more positively to opportunities to learn from peers rather than an official instructor (Bourbeau *et al*, 2004). While the literature is not conclusive about which type of approach is most successful, it does suggest that the following may promote greater effectiveness (Coulter and Ellins, 2006):

- Longer educational programmes (12 weeks or more)
- Higher intensity programmes
- Focus on specific issues rather than general educational topics
- Participative rather than didactic teaching methods
- Involvement of family or other informal carers.

### What support do people need to make informed choices?

The type of information that is needed by patients to make choices about their health care can be highly complex. Such information should not only include comparative data about different options but also guide the consumer through the

comparison process. There are many factors that may influence, for example, choice of general practitioner such as practice location, local transport links, range of services, quality of care, opening times and so on. Patients may need help to determine the relative importance of these factors and perhaps also to make trade-offs between them so that they can choose the general practice which best meets their needs and preferences.

Where an individual has difficulties understanding even basic health information this process can be fraught with difficulty. Moreover it has been shown that poor numeracy skills have the strongest – and most negative – impact on patients' ability to effectively make use of comparative information to make health care choices (Hibbard *et al*, 2007). Without help to access and use information, people who do not have basic skills will be unlikely to benefit from opportunities for patient choice in primary care.

One model for supporting patients in the choice process was tested in the London Patient Choice pilot. Twenty patient care advisors (PCAs) were employed by NHS Direct to be a single point of telephone contact for people who were choosing where to undergo their surgical treatment. PCAs played a significant role in facilitating choice and patients highly regarded the support that they received from them (Coulter *et al*, 2005). Evaluations of London Patient Choice showed that there was no difference in the uptake of choice according to social class, educational level or ethnic group. It has been suggested that groups that might otherwise not have exercised the right to choose were encouraged to do so in the London pilot because of the help they could receive from a PCA.

A similar function to that of PCAs can also be fulfilled by decision aids, which are structured tools for helping consumers to make health care decisions. There are two main components to a decision aid:

1. Evidence-based information about different options and their outcomes
2. Tools which help patients to clarify their preferences and guide them through the decision-making process.

These can be delivered in many different formats – from simple brochures, through videotapes, to interactive computer software. While some are designed to be taken home and self-administered, decision aids are intended to supplement rather than replace the patient-professional consultation.



The use of decision aids is supported by a strong evidence base; evaluations have found that they improve patients' health care knowledge, involvement in decision-making and uptake of appropriate services (O'Connor *et al*, 2003). Moreover, there is some evidence from the United States to suggest that disadvantaged groups gain the most benefit from using these tools, and their potential value as a health literacy strategy is now being more fully explored (Gustafson *et al*, 2002).

Community education approaches have also been found to be effective in supporting people. For example, in Tower Hamlets and Hackney the voluntary organisation *Social Action for Health* has trained and supported over 70 local people to act as own-language 'health guides' within their communities. Health guides share information about local services to facilitate access, and at the same time they receive feedback from participants about their service experiences which is shared with local agencies. The project was launched in 2004, and since that time has trained health guides from many different communities including Bengali, Somali, Congolese, Nigerian, African Caribbean, Angolan and Turkish/Kurdish. An evaluation of 13 specially trained mental health guides found that participants welcomed learning from a local community member and service user who could draw on their own experiences; felt motivated to change and wanted to access further sources of information about their health; and benefitted from the peer sharing and support which resulted from the group based approach (Atkinson *et al*, 2007).

## Conclusion

The ability of patients to make informed decisions about their health and health care is critically dependant on information. In recent years there has been an explosion in public information about health services – initially through NHS Direct and latterly through the NHS Choices website. These services are expanding what is publicly known about the availability and quality of local health services, and are a major step forward. Nonetheless, the evidence summarised in this paper shows that a 'one size fits all' information strategy will not be effective at meeting all information needs and abilities.

In particular, the literature we have summarised raises questions about the effectiveness of the internet, which is emerging as the government's key delivery route for information about health services and is increasingly used by local NHS organisations. Many of the groups who are least well served by the health system currently, and who therefore stand to benefit most from opportunities to exercise informed choice, either do not have internet access or lack the confidence and/or skills to search for information in this way. There is a risk that making more health information available via the internet will reinforce existing patterns of information seeking rather than empower new categories of health care consumer.

This paper has presented various alternative information formats and some of these, such as telephone helplines and digital television, are more likely to reach groups that do not access the internet or use written leaflets. But the effectiveness of information is not only influenced by the

way in which it is delivered. Evidence about the relationship between information and behaviour suggests that information alone rarely changes behaviour once it has become a habit. People are unlikely to take on a more active role in their health – for example by enquiring about the services their practice provides or changing GP – by the release of information alone.

An approach that encourages people to think about issues themselves and generate their own arguments for why it might be useful to change GP practices or use health services differently may be more effective. This would mean not only providing information which is relevant and engaging, but also creating opportunities for people to reflect on that information for their own situation and develop the skills which enable them to use it effectively. Various tools and techniques can be employed to this end: from the use of personal stories as a means of showing when and how choices can be made, to decision aids which help patients to explore their options and guide them through the choice process. Some groups will need more direct forms of support (e.g. from a patient care advisor) to access, understand and use information about the services in their area.

Information materials are frequently designed with a 'standard' user in mind, but the public is not a uniform group. If patients and the public are going to be empowered to use information about quality of primary care then the content should be relevant and designed to suit different needs; the format must be accessible to people with different literacy levels; and different modes of dissemination should be provided to enable everyone to make use of the information. It is the fit between information and its intended user which is critical.

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