

## ○ Patients make it better

### The international evidence

This is a summary of the effectiveness of strategies to involve patients in improving the quality of healthcare. It is drawn from the Picker Institute's authoritative research overview:

*Patient-focused interventions: a review of the evidence.*<sup>1</sup>



That report is international in scope. This summary, however, concentrates on findings that are of particular interest for UK healthcare.

Patient-focused interventions seek to support patients as active participants in securing appropriate, effective, safe and responsive healthcare.

There is increasing policy and professional interest in patient-centred care. But there is also resistance – suspicion that the idea is not evidence-based, and fear that empowering patients will lead to spiraling demand.

Robust research evidence is required. This overview draws together the best objective English-language

evidence on the *outcomes* of patient-focused interventions – what works and what does not. It is vital that this evidence underpins any discussion of future policy and practice in healthcare.

### IN THIS SUMMARY

Patient-focused interventions are reviewed across the following topics:

- Health literacy
- Treatment decisions
- Supporting self-care
- Patient safety
- Access to healthcare
- Service improvement using patient feedback
- Service improvement using patient choice

In each section we ask:

- What is it?
- Who wants it?
- Is it happening?
- What works?
- What needs more research?

### FIRM GROUND ON WHICH TO BUILD

*Patient-focused interventions: a review of the evidence* highlights some basic premises upon which future policies should be developed:

- policies of collaboration with patients can be built upon the substantial bedrock of positive evidence
- we cannot reduce health inequalities without tackling health literacy and involving patients in their own care
- patients can play an important role in making decisions about their treatment, in managing long-term conditions, and in making healthcare safer
- there are lots of creative ways to improve patients' knowledge and experience, the way they use services, how they look after themselves. Together all these can keep them healthier
- as interest in patient partnership approaches grows, so too will our understanding of the best ways to involve patients as active participants in their own healthcare

## Research questions and methods

### The research

The overview was produced for The Health Foundation's Quest for Quality and Improved Performance (QQUIP) programme. It asked:

- how effective are patient-focused interventions?
- what is the best practice?
- what looks promising for future research?

### The measures of effectiveness

Patient-focused interventions were assessed in relation to four categories of outcomes:

- patients' knowledge and recall of information

- patients' experience
- use of health services, and cost-effectiveness
- health behaviour and health status.

### The evidence base

The overview looked at over 150 systematic reviews published between 1998 and 2006, plus many other studies. An online search included Medline, Embase, CINAHL, DH-DATA, PsycINFO, AMED, British Nursing Index, Cochrane Library, DARE, specialist websites, and others.

*The full report (or individual chapters), including references to all the included studies, can be found in the Publications section of the Picker Institute website at [www.pickereurope.org](http://www.pickereurope.org).*

## ○ Improving health literacy



**Health professionals tend to think the information that they give patients is ample. Often, however, it doesn't fully meet the patient's needs. Most people need help to understand the causes of illness and their treatment options.**

### What is it?

Patients' involvement in their own healthcare or that of their families can only be built on an understanding of health and being able to use that knowledge. The relatively new concept of 'health literacy' describes more than just knowledge, or the ability to read information. It means being able to find, understand, and use health information to make sound decisions in one's everyday life.<sup>2</sup>

Improving health literacy is critically important in tackling health inequalities. Low health literacy is a key factor in ill health. Improving health literacy means involving patients directly in the process. It must be based on the evidence of what patients require, not on what health professionals think patients need.

### Who wants it?

The overview found that patients often want more information than they get, and professionals tend to overestimate how much they supply.

Patients' information needs are very diverse according to their age, class, gender, beliefs, preferences and coping strategies; and to their general literacy, first language, skills and abilities.

Patients' needs for information change over time. When patients first receive a diagnosis – 'you have diabetes', for instance – they need practical information to support care decisions. Later, when they focus on long term prognosis and self-care, they have more specific and in-depth information needs.

## Is it happening?

Health literacy interventions around the world have three key objectives: to provide information; to encourage the appropriate and effective use of health resources; and to tackle health inequalities.

In Canada and the United States there are examples of national programmes focusing on health literacy.

In the UK, policy has focused on health information rather than health literacy.

## WHAT WORKS?

**Health information** if it is tailored and personalised, can contribute to better health outcomes and is more highly valued by patients. For example, a trial of computer-based personalised materials using cancer patients' medical records showed that these were much more highly valued by the patients than booklets or generic computer-based materials.<sup>3</sup>

People who use computers often like getting their health information on the internet – there are at least 6,000 websites containing health information. But the internet tends to reinforce health inequalities by excluding elderly or disabled people, people with low incomes, and people from ethnic minorities. The quality of internet information is very variable and often problematic.<sup>4</sup>

What patients want most of all is information that is useful to *them* – that is appropriate, timely and relevant. Clinicians and policy makers usually think patients need mainstream medical information, such as the facts about a disease, but patients may be more interested in treatment options and their probabilities of success, or prognosis, or how to get support to manage their condition.<sup>5</sup> They want information to help them make decisions (see page 3). Likewise the information must be accessible.

This overview found that:

- good quality written information adds to patients' knowledge; personalised information has most impact; and combining written and verbal information works best of all
- information in other formats – interactive TV, audiotape, web-based – has mixed results for improving knowledge but can have beneficial effects on patients' confidence and ability to be involved in decisions; and can improve clinical outcomes and health behaviour
- information is most likely to be useful if user groups are involved in its preparation.

**Mass media campaigns** to spread targeted health information can be effective in raising awareness, but they have few direct effects on behaviour. Mass media campaigns work best as a 'background' against which other actions to change behaviour can take place.

**Low literacy interventions** that target health information at people lacking in health literacy have usually involved designing or revising health information for their specific needs. This has been more common in north America than the UK.


Studies show mixed results, with some initiatives improving knowledge and comprehension. Pictograms and other non-written communications have been welcomed by patients. There is not enough evidence to show whether these initiatives have had any effect on health inequalities.

#### What needs more research?

- The impact of health literacy campaigns on health status and behaviour.
- The cost-effectiveness of health literacy campaigns.
- The effectiveness in reducing health inequalities.



## ○ Improving treatment decisions

 **Not being properly told about illness and the options for treatment is the most common cause of patient dissatisfaction.<sup>6</sup> Most patients want more information and a greater share in the process of making decisions about how they will be treated.**

### Shared decision-making - what is it?

Shared decision-making is "a process in which patients are involved as active partners with the clinician in clarifying acceptable medical options and in choosing a preferred course of clinical care".<sup>7</sup> It is closely linked to, but not the same as, the processes of obtaining informed consent and communicating risks.

Shared decision-making is appropriate in any situation where there is more than one reasonable course of action, and no one option is self-evidently best for everyone. This situation is very common since there are often many different ways to treat a health problem, each of which may lead to a different set of outcomes.

Central to sharing is a two-way exchange between the patient and the professional. The health professional acts as the expert on the effectiveness, probable benefits, and potential harms of the treatment options, and shares that information with the patient.

The patient acts as an expert on herself, and shares information about her social circumstances, attitudes to illness and risk, values and preferences. These factors may have a strong influence on weighing the appropriateness of any treatment and should be accepted as legitimate in the decision-making. Also accepted is the patient's shared responsibility for the decision and for any risks taken.

### Who wants it?

Not all patients want to share making the decisions. Older people are more likely to want the doctor to decide. People who are relatively healthy may want to be more involved – in decisions about screening, for instance – than those who are very ill.<sup>8</sup>

What is important is that the health professional should not make assumptions, based on their observation of the patient, about the degree of involvement they desire. The professional should always find out those preferences through communication.

### Is it happening?

Official approval for the underlying principles is widespread. In the UK the General Medical Council, the British Medical Association, and the Department of Health are all committed to it. The Health Ombudsman's report for 2004 also stressed the importance of making sure that patients understand the options for their treatment.

There is evidence that doctors increasingly support the principle.

But the evidence shows that true sharing of decisions is not yet widely practised.<sup>9</sup> Doctors often fail to explore patients' values and preferences. They focus on the disease not the person. Although doctors talk to patients, and know this is important, they often dominate the discussion, while patients remain passive, withhold information, and do not voice their preferences.

National NHS patient surveys in England show that 31% of primary care patients (2006), 48% of hospital inpatients (2006), 30% of outpatients (2004) and 60% of mental health patients (2007) did not feel they were involved in decisions as much as they wanted to be.

## WHAT WORKS?

The overview examined the evidence for the three main ways of improving clinical decision-making:

- communication skills training for clinicians
- coaching and question prompts for patients
- patient decision aids.

**Training** does improve the communication skills of doctors, nurses and pharmacists.<sup>10</sup> Patients get greater involvement, their knowledge improves, their anxiety lessens and they feel more satisfied.

This does not significantly increase costs. By reducing the number of prescriptions issued it may bring down costs. People stick to their course of medicine better (adherence). There is a need for more evidence about the effect of this on health outcomes, but it is clear that it is possible to make a significant difference to the way professionals communicate with patients.

**Patient empowerment techniques** help patients take a more active role. They include coaching; cards that prompt them on questions to ask; diaries or topic lists for discussion; and summaries of consultations for later review.

Patients' knowledge and recall is improved; they feel more involved and in control. There is no evidence that this active role prolongs consultations – so it does not increase costs. Evidence about whether it improves physical health is mixed.

**Patient decision aids** are evidence-based tools to supplement the exchanges between patients and professionals. There are more than 400 available internationally.<sup>11</sup> They use various media (books, computer programmes, audiotapes and so on) to help patients work out their values and preferences, and make decisions in relation to the pros and cons of the available treatment options.

Patients' knowledge improves; they get greater involvement and a better match between their values and the treatment chosen.<sup>12</sup> Decision aids do not either increase or decrease anxiety, but they do give

patients a more accurate perception of risk. The more individualised the risk information, the more likely to affect the treatment choice.


There is evidence that for some treatments and conditions cost-effectiveness increases. For example, patients are more likely to take up appropriate screening and they are less likely to opt for surgery.

### What needs further research?

The strong evidence in favour of shared decision-making suggests the next research priority is to discover and overcome the barriers to its implementation. This is especially important in:

- professional educational curricula
- clinical governance (quality management)
- plans for improving the quality of health services.

## ○ Improving self-care

 **Professional healthcare is the tip of an iceberg. Self-care – that is, people's own active involvement in all aspects of their healthcare and that of their families – accounts for up to 85% of healthcare.**

### What is it?

Most self-care consists of the day-to-day management of long term and chronic illnesses, such as asthma, diabetes and arthritis. The growing caseload of these conditions is a major future challenge for the health service. The 17 million people in the UK<sup>13</sup> with at least one chronic illness are heavy users of healthcare. They generate 80% of all GP visits; 60% of hospital bed use; and two thirds of emergency hospital admissions.<sup>14</sup>

The care needs of chronically ill people are different from those of acute patients for whom the NHS was designed. Top-down delivery to a passive patient will not work. The patient, at home, among their family and friends, will do most of the caring. The professional's role should be to encourage, facilitate and support them to look after themselves safely and confidently, to live as normally as possible and to cope with the emotional impact of their illness.<sup>15</sup>

### Who wants it?

Most people with long term conditions have expressed some interest in more actively managing their health.<sup>16</sup> There is some evidence that patients welcome strategies to support this, such as being allowed to record their wishes on their medical records.

But not all patient views are positive. Take-up of self-management education has sometimes been poor, and drop-out rates have been as high as 50%. Patients particularly need good relationships with professionals, and confidence that they will be fully supported, before taking greater responsibility for their own care.

## WHAT WORKS?

There have been many different interventions designed to help people to care for themselves, and a mass of research exists. But many studies were poorly designed, and there are significant knowledge gaps.

**Patient education for self-care** has largely been concentrated on self-management education programmes, as has most research.

Information-only education programmes (with no participative studying) have little effect on self-care. Information alone does not change people's behaviour or produce better health outcomes.<sup>17</sup> Active education, teaching practical skills, is always more effective.

This could be delivered via computers. Two systematic reviews of interactive applications suggested patients' knowledge and abilities improved, they felt they had better social support, and their health behaviours and outcomes could improve.<sup>18</sup>

Most education programmes, however, are delivered in classrooms where people study together. Where these are organised for people with **specific diseases**, some have been very effective. For example, diabetes patients gained strong health benefits from self-management education, leading to its approval by NICE;<sup>19</sup> and people with depression, eating disorders, asthma and hypertension also benefited. However, others are less successful: arthritis patients gained knowledge and some psychological improvement, but no lasting health benefits.<sup>20</sup>

Most attention now is focused on **generic** education programmes – that is, for patients with all forms of chronic conditions. Self-management courses led by patients themselves were developed at Stanford University, USA, and involve attending a six-week course. Participants learn about relaxation, managing depression, fear and anger, as well as nutrition, problem-solving, managing medication, sharing treatment decisions and making plans for future care.<sup>21</sup>

The Stanford programmes have been extensively researched and are shown to improve health behaviours, patients' abilities, and the use of health resources. But it is not known whether these initial benefits are sustained over time (some evidence suggests not).

In the UK, after early work by patient-supported voluntary organisations, the Department of Health created the Expert Patient Programme (EPP), based on the Stanford model, with 100,000 places planned by 2012.

The initial evaluation of the EPP was not very positive. The majority of patients went for social reasons – to share their experience and support others – and viewed the programme as reinforcement rather than a source of new learning. They said condition-specific courses could have taught them more.<sup>22</sup> It has sometimes been difficult to attract participants, especially those from disadvantaged groups.

The overview reached the following conclusions about education programmes for self-management:

- longer programmes, with greater intensity, have larger effects
- education programmes are more effective where they are combined with the patient getting regular reviews with a health professional, especially if they follow a personal action plan together.

**Direct support** for self-care could be more important than educational courses, but there is a need for more evidence. Examples include:


1. Patient-centred **telecare** – providing people with support over the phone to their homes – can reduce social isolation, improve people's confidence and ability to cope, and improve their quality of life and reduce depression. Where it replaces routine personal home visits or clinic visits it saves costs.
2. Providing **access to medical records** increases patients' sense of control, but few other benefits have been proved. Providing audiotape records of consultations improves patients' knowledge and recall.
3. There are few systematic studies of the benefits of **self-help groups and peer support**. The evidence shows patients welcome this support, gain knowledge, and improve their coping abilities, but there are few other benefits. Women may gain more than men. Particularly isolated groups gain the most.
4. **Self-monitoring' and 'self-treatment'** includes things like encouraging patients to monitor their own blood pressure or administer their own anticoagulation therapy. There are some positive clinical results – health status can be as good as in routine healthcare, some risks are reduced, some cost savings may be possible. But there were few provable benefits in terms of patients' knowledge, experience and sense of control.

### What needs further research?

Most studies measured only short term outcomes, and overlooked the financial side. More needs to be known about:

- long term benefits
- cost-effectiveness
- the comparative effectiveness of different approaches
- which elements of interventions provide most benefit.

## ○ Improving patient safety

 Patients can be crucial partners in developing a thoroughgoing safety culture. Their involvement should be valued and supported. Listening carefully to patients improves their safety.

### What is it?

Involving patients in improving safety requires conscious communication strategies, and the creation of mechanisms for patients to report safety issues.

If patients' understanding of health topics is poor (see 'health literacy') it can endanger their safety.<sup>23</sup> For patients to point out treatment lapses requires that they have some knowledge. Therefore, telling them what to expect from treatment or procedures can help them speak up when quality of care falls short. This requires courage on the patient's behalf, and the courage of staff and managers actively to invite such reporting.

### Who wants it?

Patients want more openness about, and disclosure of, medical errors.<sup>24</sup> Although patients' desire to be part of safety campaigns has not been measured, patient surveys do show strong levels of concern about safety-related issues such as hospital cleanliness, information on medicinal side-effects, and understanding test results.

### Is it happening?

The UK has had a major programme to improve patient safety since 2001, but with little recognition of patients' potential to take an active role.

## WHAT WORKS?

This is a fairly new area of research, but there is evidence to suggest several ways in which patients can help to improve safety in healthcare.

**Patient involvement in infection campaigns** can be helpful. A UK pilot study encouraged patients to remind staff to wash their hands, while staff were given 'It's OK to ask' badges. It has been estimated that the resulting improvement in hygiene, repeated nationwide, could save £140 million and prevent 450 deaths every year.<sup>25</sup>

**Various strategies have been tried to improve medicine-taking** to avoid harmful effects. Of these the most effective involve simplifying dosing regimes, but better communication can help too. More user-friendly information about medicines is urgently needed to prevent patients making medication errors. Also, if patients could directly report adverse drug side-effects to the drug safety agencies, this would reduce the time it takes to spot problems (since doctors are slower to report). If they are told what to expect, patients can monitor medicine side-effects, use equipment correctly, and watch for complications after they leave hospital.


**Patient access to their medical records** enables patients to find and correct mistakes, reducing the risks caused by inaccurate records.<sup>26</sup>

With the trend towards care outside big hospitals and more self-care, patients' potential contribution to safety is increasing. But this does not mean that health professionals can slacken their own drive towards safety. In particular, improving the way new services are set up, sometimes with risks to safety (latent failures) concealed in them, must be a matter for urgent attention.

### What needs further research?

- In what ways do patients want to be involved in safety improvement?
- Where could it have most impact?
- Which techniques are most effective in encouraging patients to raise safety concerns with staff?

## ○ Improving access to healthcare

 The people who need the NHS most are often the ones who get least access to it.<sup>27</sup> Tackling this involves dismantling a range of barriers. Certain groups face particular problems, including people living in rural areas, members of ethnic minority groups, homeless people, prisoners and asylum seekers.

### What is it?

'Access' has several dimensions. It includes the availability of services; whether they are the right 'fit' for their target users; their physical accessibility; and issues of equity (access for all regardless of status).

Initiatives to improve access may address the overall supply of services, or the reduction of inequalities, for example by specifically targeting groups who face the biggest barriers. New modes of access may seek to reduce the need for face-to-face consultations, allowing them to take place by phone, email or video link.

### Who wants it?

Access is a big issue for patients. Long waiting times always cause concern. In surveys people say they want choice about where they receive care, but that access to a good local service is far more important to them. Exercising the former may put the latter at risk.

### Is it happening?

In the UK patients report real improvements since 2001 in access to GPs and waiting times for hospital appointments and procedures.<sup>28</sup> It is important to sustain these. There is increasing demand from patients

for more flexibility in the opening times of GP surgeries and clinics; and evidence that lack of convenience can deter people from seeking consultations.<sup>29</sup> New kinds of services offering this convenience and flexibility have recently been trialled.

## WHAT WORKS?

Patients report good experiences with the new ways of accessing health advice. But patient satisfaction is only part of their aims. Key questions are: who do they serve, are they cost-effective, and do they have good or bad effects on the overall use of services?

**Walk-in centres** offer an alternative to GPs, are located in busy areas such as high streets and train stations, are open outside normal GP hours, and are run mainly by nurses. Patients like them (almost 80% report satisfaction), but they serve mainly young, male, affluent groups who value flexibility more than the continuity of care that GP surgeries offer.<sup>30</sup>

The cost of a consultation appears to be higher, in part because a nurse-led consultation takes more time and leads to lengthier investigations. Around a quarter of patients may be using the centres as an alternative to A&E, which may mean better use of resources. On the other hand, between one third and one half of the patients go on to consult their GP about the same problem, suggesting they are duplicating, rather than substituting for, standard primary care services.<sup>31</sup>

**NHS Direct** is a 24-hour advice and information phone service, again run by nurses. It is backed by a website and limited digital TV information. Again, users are generally satisfied with it.

NHS Direct is one of a number of 'telecare' services that have been studied in randomised controlled trials. Telecare increases patient satisfaction. It improves access for some, such as people in rural isolation or with physical or work-related constraints; but not people without telephones or with language barriers.

It can reduce the immediate workload for GPs, but many patients appear to reconsult later. There is no clear evidence on whether patients are diverted from A&E, the usage of which continues steadily to rise.<sup>32</sup>

**Remote teleconsultation** through video conferencing has the potential to reach remote or hard-to-reach groups, if a physical examination is not needed. Virtual consultations appear more effective on health outcomes in some specialties than others. But they can be more, not less costly for the service to provide – though they save travel costs for patients and may reduce the number of tests and investigations.

**Specialist outreach clinics** bring consultants out of hospitals and into GP surgeries and community settings. There is strong evidence that this improves access for patients, and reduces their travel time and costs.

It improves doctor-patient communication and increases patients' satisfaction. There is some evidence of improved adherence to medicines, and better health outcomes, notably for older people with mental health problems.<sup>33</sup>

### What needs more research?

- Whether new access points duplicate existing services or reduce demand for them.
- Which types of intervention could most help the people who most need better access – such as socially excluded, homeless and ethnic minority groups.
- Which settings and groups are most effectively served by specialist outreach.

## ○ Improving the care experience through patient feedback



What patients say about services provides valuable information for anyone designing or seeking to improve healthcare.

### What is it?

Complaints are one way patients can make their views known. Another is to exercise choice (where it exists), voting with their feet: we cover this in another section (see page 8). Advocacy can also bring patients' feedback into the system, as can patient experience surveys and focus groups. Complaints, choice and patient feedback together make a considerable volume of 'customer'-focused information available to service providers.

### Is it happening?

Every NHS trust in England is required to survey its staff and patients annually as part of the national survey programme. Similar programmes are being considered in Scotland, Wales and Northern Ireland. Trusts must also maintain complaints systems. Most hospital trusts have a Patients Advice and Liaison Service; but other advocacy services, for example for specific patient groups, are thinly spread. The evidence that the health service uses this customer feedback for service improvement, however, is mixed.

## WHAT WORKS?

Patient experience surveys of hundreds of thousands of patients, in the UK and in other advanced, industrialised countries, have identified eight key aspects of healthcare that patients consider most important:<sup>34</sup>

- fast **access** to reliable health advice
- effective **treatment** delivered by **trusted professionals**



- **involvement** in decisions and respect for preferences
- clear, comprehensible **information** and support for **self-care**
- attention to physical and environmental needs
- emotional support, empathy and respect
- involvement of, and support for, **family and carers**
- **continuity** of care and smooth transitions.

Evidence shows an association between poor quality patient experience and:

- worse health outcomes
- increased legal action
- increased demand to change provider.

National survey results can trigger national action:

- the NHS 2006 survey of primary care patients prompted ministerial action when it showed that doctors were not following guidance on copying their correspondence to their patients
- consistent feedback from inpatient surveys showed that many patients still experienced mixed-sex hospital accommodation after the NHS said it had been eliminated, prompting action by the Chief Nursing Officer.

Surveys can also benchmark progress against national policies or targets. Trends tracked across the NHS patient surveys since 2001, for example, clearly show patients experiencing the beneficial impact of reduced waiting times for GP and hospital appointments and hospital treatment.<sup>35</sup> By contrast the annual primary care surveys have shown slower-than-promised progress in offering patients a choice of hospital.<sup>36</sup>

Some studies demonstrate that patient experience surveys *can* be used to prompt service improvement, and to measure its progress over time.<sup>37</sup> Every individual NHS trust is able potentially to use its data in this way, and experience suggests many do.

But systematic research evidence of such usage does not exist. Where studies show that patient feedback has improved services, it is often as part of complex change processes where other factors are also important.

**Making a complaint** is complex and time-consuming in England; complaints procedures are fragmented and not well-handled. There is a small amount of evidence that complaints have driven improvements, for example in mental health services.


But the Parliamentary and Health Ombudsman for England said in her 2005 report on complaints, 'the NHS is not using the valuable information ... to improve its services' and in her 2006-07 report that 'there was little progress nationally this year towards improved complaints handling'.<sup>38</sup>

**Advocacy** services are one way of helping patients get redress. They are proven to help marginalised groups such as those with low literacy and homeless people.<sup>39</sup>

#### What needs more research?

- The impact of public reporting of patient survey results.
- The best ways to organise complaints systems.

## ○ Improving care through patient choice

 One justification for recent reforms in the NHS has been that if patients are given choice, and can 'vote with their feet' by changing provider, it will provide incentives for providers to improve their services.

### What is it?

Patient choice in the NHS mainly focuses on the choice of provider. When referred by their GP to a hospital, patients should have a choice of at least four (in 2007), but eventually of all, hospitals to attend. More recently pregnant women have been formally guaranteed some choice of where to give birth.

### Who wants it?

Patients do want this choice and will carefully consider it when it is offered. However, patients say it is not the most important kind of choice – having a say in decisions about care and treatment options, or a choice of doctor, both seem more important to them.

### Is it happening?

The government's target for all referred patients to be offered a choice of hospital by early 2007 was not met. Halfway through the year only around half of patients were being offered a choice by their GP. There is more choice in the US and some European health systems, but most of the research evidence is US-based.



## WHAT WORKS?

**Personally choosing a doctor or hospital** increases patient satisfaction and makes them less likely to want to change again. Choice pilot schemes like the London Patient Choice Project were popular with, and well used by patients.<sup>40</sup> The provision of free transport, and dedicated personal support, meant that these choices were equally accessible to all. Without such support there is a danger that better-off people will take undue advantage of the new options for choice, thus increasing health inequalities.

**Informed decisions** require a mix of information: will an alternative hospital reduce a patient's waiting time; will it increase travel costs and barriers for them and their families; who will carry out follow-up care; what is the reputation of the local hospital? In this mix, patients say that information about performance and clinical quality is just as important as practical arrangements.<sup>41</sup>

In the UK some hospital data is now published, though patients may not know about it. Patients say there is still a gap between the performance information they need and what is available. Little is yet known about what information might best help UK patients choose providers.


In the US, publication of hospital data stimulated the providers to try to improve services but it may not have changed patient behaviour – patients rarely mentioned comparison of health outcomes as a factor influencing their choice of provider.<sup>42</sup>

So far there is no hard evidence that choice of provider will have an effect on service quality, although publishing information about the quality of care in different hospitals might do so. Will providers that find themselves less popular improve the quality of their services; or avoid treating the sickest patients to make their figures look better?

### What needs more research?

- What information and support do patients need for choice?
- What are the positive and negative effects of publishing performance data, and what are the best means of presenting and disseminating it?
- Does provider choice have any impact on equity, costs, use of resources and health outcomes?

## ○ Improving service development through public involvement

 The overview's examination of evidence relating to public involvement in decision-making in the NHS concluded: "without adequate resources – including funding, staff time and training – public involvement initiatives are likely to fail, or will have limited impact on service development".

### What is it?

In the NHS, 'public and patient involvement' have traditionally been yoked together, but they are different in nature and purpose. 'Public involvement' means lay involvement in organisational decision-making. Levels of public involvement vary, and expectations of 'participation' or 'partnership' vary between different groups of people.

Public involvement is about "understanding differences, finding common ground and negotiating mutually agreeable solutions...valuing alternative perspectives and thinking about things in new ways".<sup>43</sup> There is a wide spectrum of possible involvement mechanisms, from information-giving, through formal consultation, to full user control.

### Who wants it?

The vast majority of patients (90% in one 2006 survey<sup>44</sup>) think local people should have a say in how the NHS is run. However, recruiting people to be actively involved is often difficult. Many barriers to involvement have been identified, including public scepticism about the validity and likely impact of consultations, and people's lack of confidence in their knowledge and ability.

### Is it happening?

Since 2001 all NHS organisations have been obliged by statute to involve and consult patients and the public about their plans.

Foundation trusts are able to have a degree of self-governance, where public involvement is provided by having a community-derived 'membership' to help guide the Board.

Public involvement is particularly important for primary care trusts (PCTs) which are responsible for meeting the health needs of whole geographical populations. But public and patient involvement is the least developed part of their clinical governance agenda.<sup>45</sup> PCTs mainly ask people about redesigning services, and hold regular meetings with community groups, but there is little ongoing involvement of the local population in setting priorities or holding providers to account.<sup>46</sup>



## WHAT WORKS?

There is ample evidence that people generally like being involved; they feel more confident and knowledgeable about the health service. But other outcomes, such as wider benefits to the services themselves, or the cost-effectiveness of the processes, have scarcely been touched on. Primary care trusts themselves have expressed low expectations that the process of public involvement will actually affect their commissioning decisions.

**The process of involving lay people in decisions**, is where most evidence lies. We know something about the barriers to involvement. These include:

- people feeling unclear about what will be expected of them
- resistance from health professionals and managers
- concerns about whether people who get involved represent all sections of the community and
- a shortage of money and skills for the process.<sup>47</sup>

Citizens' juries can be effective in overcoming the shortcomings of other methods of public involvement, by giving the public a clearer role, giving them the time and support to make considered decisions, and allowing those decisions to have a clear impact on services. But they are expensive, making cost-effectiveness an unresolved issue.<sup>48</sup> Other creative approaches, such as ongoing patient panels, are being tried, but as yet the evidence is not available to conclude which forms of public participation work best, and in what circumstances.

An urgent task is to work out the yardsticks for assessing success.

### What needs more research?

- A coherent and agreed evaluation framework for public involvement, able to measure its effects against its objectives.

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## WHAT WORKS? SOME KEY FINDINGS

### Health literacy

- Tailored, personalised information is very helpful.
- Combining written and verbal information works best of all.
- Interactive TV, audiotape, and web-based information work can improve patients' confidence and involvement, leading to better clinical outcomes and health behaviours.
- Written information works best when patients or user groups are involved in its preparation.

### Shared decision-making

- Patient decision aids improve patients' knowledge and involvement, resulting in more accurate perceptions of risk and, in some cases, increased cost-effectiveness.
- Communications skills training for health professionals can lead to improvements in patients' knowledge, involvement and adherence to treatment choices.
- Encouraging patients to ask questions can help to improve their knowledge and recall of information.

### Self-care

- Written information on its own is of limited effectiveness – it needs to be coupled with education from health professionals.
- Self-management education programmes for specific diseases work best if they are well-designed, intensive, and reinforced in regular consultations with health professionals.
- Lay-led self-management courses can help some patients with improvements in knowledge, coping behaviour and symptom control, but not all.
- Computer-based self-management information combined with other forms of support can improve knowledge, health behaviours and clinical outcomes.
- Self-monitoring or remote telemonitoring, for example in hypertension, heart failure and anticoagulation therapy, can be cost-effective.

- Self-help groups can be useful for helping people cope with the effects of disease, giving them a better sense of social support.
- Patient-held records lead to an increase in patients' knowledge and sense of control and can also improve the accuracy of the records.
- Telephone support can reduce social isolation, improving patients' confidence, coping ability, emotional health and quality of life.

### Safety

- Encouraging patients to ask health professionals if they have washed their hands improves hygiene and infection control.
- Simplifying dosing regimes improves patients' ability to take their medicines as recommended.
- Information, education and involvement in treatment decisions, coupled with reminders and other support, improves adherence to medicine regimes.

### Access

- New ways of accessing health advice (walk-in centres, phone help lines) are popular but they may not help to reduce the workload in more traditional forms of care.
- Remote video consultations and outreach clinics have been shown to improve patients' access, but they have not yet been shown to be more cost-effective than conventional approaches.
- Telephone reminders and telephone consultations are popular, effective and safe.

### Patient feedback

- Patient experience surveys can be used to stimulate quality improvements, especially when used as part of a broader strategy for improving care.
- Making hospital performance data publicly available can encourage healthcare providers to implement quality improvements.
- There is an association between poor quality patient experience and worse health outcomes. Also, patients who report worse experience of communication with health professionals are more likely to take legal action.

### About the Picker Institute

The Picker Institute works with patients, professionals and policy makers to promote understanding of the patient's perspective at all levels of healthcare policy and practice.

It undertakes a unique combination of research, development and policy activities which together work to make patients' views count.

It is an independent, not for profit research and development institute with charitable status.

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