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# Implementing shared decision making in the NHS

Creation of a platform of tools to provide information to doctors and patients should be the first step in giving patients choice about their treatment, say **Glyn Elwyn and colleagues**

Policies to promote shared decision making are becoming prominent in the United States, Canada, and United Kingdom.<sup>1-3</sup> This is partly because of a recognition of the ethical imperative to properly involve patients in decisions about their care<sup>4-5</sup> and partly because of the accruing evidence that the approach has benefits.<sup>6</sup> Shared decision making is an approach where clinicians and patients make decisions together using the best available evidence. Patients are encouraged to think about the available screening, treatment, or management options and the likely benefits and harms of each so that they can communicate their preferences and help select the best course of action for them. Shared decision making respects patient autonomy and promotes patient engagement.

Despite considerable interest in shared decision making, implementation has proved difficult and slow.<sup>7</sup> At least three conditions must be in place for shared decision making to become part of mainstream clinical practice: ready access to evidence based information about treatment options; guidance on how to weigh up the pros and cons of different options; and a supportive clinical culture that facilitates patient engagement. This article outlines some options for creating a sustainable decision support platform for patients that may facilitate a wider adoption of shared decision making in clinical practice.

## Decision aids

Interventions to support patient decisions, often called decision aids, have been developed to provide evidence based information to patients.<sup>8</sup> These tools are usually designed for situations where there is some uncertainty about the best treatment option and provide information about the harms and benefits in as balanced a way as possible. Some tools are short and can be used in consultations<sup>9</sup>; others are longer, such as DVDs, booklets, or web tools that patients use before consulting a clinician.

Decision aids are appropriate when more than one course of action is feasible (clinical equipoise) and where the best decision depends on the patient's reaction to the outcome probabilities. These are known as "preference sen-

sitive" decisions.<sup>10</sup> Examples include breast conservation surgery or mastectomy in early breast cancer, treatments for benign prostatic hypertrophy or menorrhagia, and managing knee osteoarthritis.

## Evidence of benefit

A large number of decision aids are now available, most of which were developed in North America. The latest iteration of the Cochrane systematic review includes 55 trials<sup>6</sup> and provides evidence that patients who have used these tools are better informed (mean difference 15.2/100 95% confidence interval 11.7 to 18.7) and less passive in decision making (relative risk 0.6, 0.5 to 0.8). There is some evidence that when patients have made well informed decisions, they also adhere better to treatment regimens<sup>11</sup> and that when informed patients face discretionary surgery, they make more conservative decisions, often deferring or declining interventions (relative risk 0.8, 0.6 to 0.9).<sup>6</sup> These effects seem to be strengthened when patients are given decision coaching (a brief discussion with a trained facilitator) to help them with the process of deliberation.<sup>12-13</sup>

In short, there is consistent evidence that decision support interventions designed for patients ensure that the ethical imperative of informed patient choice and consent is met, with a range of benefits for patients. In some examples, especially where there are choices between more and less invasive options, these may lead to cost reductions; the Cochrane review of decision aids found that, in some contexts, they could reduce rates of elective surgery by 25%. This means that the NHS might be able to save considerable amounts if shared decision making, supported by decision support, could be achieved before common elective surgical procedures. Shared decision making might also reduce the likelihood and cost of litigation, although there is no formal evidence for this yet.

## Putting tools into practice

The pioneer in setting up an organisation based system for implementing shared decision making is the Dartmouth-Hitchcock Medical Center

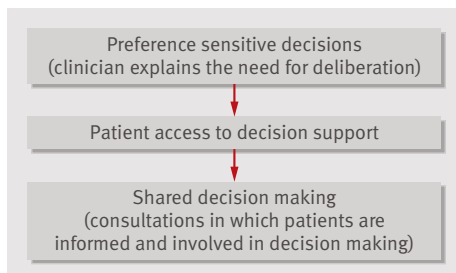
in New Hampshire, which is linked to Dartmouth College. Eleven years ago, it started using decision support tools produced by the Foundation for Informed Decision Making in Boston for a few important areas such as breast cancer, orthopaedics, and urology. Today, its Shared Decision Making Center has over 30 DVD based patient decision support tools.<sup>14</sup> Many of the centre's clinicians have integrated these tools into their workflows and electronic records, reporting that consulting with patients after they have had an opportunity to use the tools enhances the clinical encounter.

Since its launch in 1999, the centre has loaned 24 750 video, paper, and electronic decision aids for use by patients and review by clinicians. Despite its local success, the centre remains unique in the United States, although other implementation projects are in progress in primary care and other settings.

The NHS has a longstanding interest in decision aids and has invested in piloting and adapting the tools developed by the Foundation for Informed Decision Making for prostate cancer, benign prostatic hypertrophy, and osteoarthritis of the knee.<sup>15</sup> Anglicised adaptations of the DVDs and patient booklets have been distributed to urology departments throughout England, and the programme is being publicised at conferences and specialty meetings. In addition, the NHS Screening and Cancer Screening Programmes and Cancer Research UK have worked with the decision laboratory at Cardiff University to develop web based decision support for patients considering being tested for prostate specific cancer antigen (Prosdex, [www.prosdex.com](http://www.prosdex.com)<sup>16</sup>) or facing a decision whether to have mastectomy or breast conserving surgery (Bresdex, [www.bresdex.com](http://www.bresdex.com)). These initiatives are important, but the tools are not sufficient on their own. The next challenge is how to embed shared decision making and the use of patient decision support in the fabric of the NHS.

## Implementation strategies

The Health Foundation has funded a programme to learn more about how to achieve a wider implementation of shared decision making.<sup>17</sup>



**Fig 1 | Decision support as part of a referral pathway in the NHS**

This initiative coincides with the efforts by the East of England Strategic Health Authority, commissioned by the Department of Health, to accelerate the adoption of patient decision support as a means of implementing shared decision making. The health authority has commissioned NHS Direct to pilot three web based patient decision support tools. The decision aids, produced originally by the Foundation for Informed Decision Making, have been adapted for online use by patients with osteoarthritis of the knee, benign prostatic hypertrophy, and prostate cancer. Eight NHS pilot sites have been chosen and asked to identify patients who have been referred for specialist advice and who are at key treatment decision points. These patients are asked to access the interactive web based decision support system before they attend their outpatient appointment so that they are better informed (figure). Patients who do not have access to the internet are provided with a telephone number for information advisers at NHS Direct, who will also post them a copy of equivalent information. While using the interactive system, patients are asked to complete a survey to gauge the severity of their symptoms and their initial treatment preferences. This is summarised and available to them and their clinician at a later date. The logistics, feasibility, and effect of this approach are being evaluated.

For conditions that can be diagnosed reliably in general practice, it might be more appropriate to make patient decision support available before referral, perhaps by embedding them in primary care electronic health record systems. Providers of supplementary information, such as the Map of Medicine, could provide decision support for patients alongside the evidence based decision support they provide for clinicians. For other health problems where self care is a feasible option, information providers such as NHS Choices could include decision support in their public facing websites. Commissioning consortiums might want to ensure that decision coaching is provided as part of telecare services for people with long term conditions. Together, these various means could make patient decision support readily available for a wide range of topics.

### Organisational culture

Although it is clear that patients desire and value information about treatment choices,<sup>18 19</sup> it is difficult to embed the attitudes, skills, and interventions into routine practice.<sup>7</sup> Many barriers are cited, including concerns about insufficient time and lack of fit into organisational routines. Professionals often claim that there is no need for this approach because shared decision making already occurs,<sup>7</sup> but the available evidence contradicts this assertion.<sup>20 21</sup> The latest results from the Care Quality Commission's national patient surveys show that 48% of inpatients and 30% of primary care patients would have liked more involvement in decisions about their care.<sup>19</sup>

Research on shared decision making has focused mostly on the creation of tools to support patient involvement in decisions and much less on how to create a culture where professionals espouse shared decision making as a skill and routinely use these tools. Achieving this aim will require multiple approaches, including strategies such as social marketing, engagement of clinical champions, support from other organisational leaders, and measurement that focuses on relevant aspects of patients' experience such as their degree of deliberation and attainment of skills in shared decision making.

### Challenges to implementation

Substantial challenges still need to be met. Producing and updating decision support for patients is expensive: it requires meticulous attention to the accuracy of evidence as well as designing information that is easily understood by patients with different backgrounds and literacy levels. Adapting tools rather than re-inventing would be wise for the NHS given the time and resources required. Tools should meet a quality standard, and a process to assess quality will be required.<sup>22</sup>

Perhaps the biggest challenge is to ensure that decision support materials are accessible to both patients and clinicians and that they fit into clinical workflows.<sup>23</sup> This is important because these tools give clinicians access to summarised evidence about the harms and benefits of options just as much as they provide it to patients. Tools that provide short summaries for use in clinical encounters alongside longer sources of information that patients can access at home may be more readily adopted by clinicians.<sup>8</sup>

Building patient decision support into the NHS will require substantial investment and a collaboration between many agencies. Many of the building blocks are in place. High quality decision aids for many conditions already exist, although it would also be necessary to establish

a system for regular review and updating. The results of the NHS Direct pilot will show whether it is possible to build systems that provide useful links between frontline NHS clinics and tools that are hosted online. Success will require strong strategic leadership, commissioning of high quality content, and the provision of sustained funding to host these resources using computerised, online, or telephone supported channels. If such a platform could be created, it would go a long way towards developing a patient led revolution in health care—one that is fuelled by evidence.

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# Do patients want a choice and does it work?

The government in England wants to give patients more choice about their healthcare.

But **Angela Coulter** argues that treatment choice is more popular with patients than provider choice, with much greater evidence of benefit

"Nothing about me without me" was the guiding principle adopted by 64 participants from 29 countries at a 1998 Salzburg global seminar convened to develop ideas for improving the quality of health care by involving patients.<sup>1</sup> The catchphrase has now resurfaced in the coalition government's new plan for the NHS in England, which sees patient choice and shared decision making as key mechanisms to create a patient centred and quality focused NHS.<sup>2</sup> The government wants to extend the offer of choice beyond what is currently available to include choice of specialist team, choice of general practice, and choice of treatment.

The introduction of choice and market competition into the NHS has been highly controversial. The debate about provider choice centres on its effect on quality, service development, equity, and patient empowerment (table). Many people have argued passionately for and against the policy

on the basis of their expectations of its effects, but research evidence to confirm or refute these assumptions is only now beginning to emerge.

In contrast, evidence about the effects of engaging patients in treatment choices has accumulated over some time, but the findings have been largely ignored. Although only a small minority of people want to switch providers, patient surveys show a large unmet demand for greater involvement in treatment decisions that has persisted over the past eight years (figure). The government's determination to introduce wider choice and shared decision making may be challenging to implement.

## Choice of specialist

The right to choose where to receive specialist care is not a new idea for patients in England. After several pilot projects, choice at the point of referral was introduced from December 2005.

Patients could choose where they were referred to, rather than an individual specialist, and a website, NHS Choices ([www.nhs.uk](http://www.nhs.uk)), was set up to publish information on quality indicators to inform people's choices. In 2008 the available choices were extended to include any hospital in the country, including private hospitals, and a legal right to choose was enshrined in the NHS constitution.<sup>3</sup> The latest white paper promises that this will be extended to enable patients to choose the specialist clinical team that will provide their treatment.<sup>2</sup>

Pilot studies of patients offered a choice while on the waiting list for elective surgery showed that a choice of treatment location was popular and uptake was high. When patients waiting for cardiac surgery were offered the choice of going to another hospital with a shorter waiting list, half of them opted to do so, sometimes travelling long distances.<sup>4</sup> Similarly, a high proportion (67%) of patients in London awaiting various elective surgical procedures opted for alternatives to their local hospital when given the choice, and there was no evidence of socio-economic differences in uptake.<sup>5</sup> One of the most startling findings from the London patient choice pilot study was that over two thirds (68%) of those eligible for the scheme were not offered the option of going to an alternative hospital, pointing to a reluctance on the part of clinicians or managers to encourage choice.

## Arguments for and against provider choice

Domain	For	Against
Quality	Leads to better patient experience, safety, and clinical effectiveness	Increases fragmentation, reduces continuity, undermines population based services
Service development	Improves access, increases plurality of providers, encourages innovation	Increases privatisation, destabilising existing NHS providers
Efficiency	Drives down costs, increases value for money	Increases transactions costs, requires spare capacity so is wasteful
Equity	Gives benefits of choice to those currently disadvantaged and disempowered	Increases inequalities because disadvantaged people can't take advantage of choice; choice isn't feasible in rural areas
Patient empowerment	Enhances patients' influence and improves responsiveness	Many patients don't want to choose; patients won't travel; increases demand to unsustainable levels

But government policy changed before the results of the pilot projects were published, and the hospital choice scheme that was rolled out in England differed from the pilot in many ways, not least in the much more limited availability of personal support and free transport and the fact that choice was to be offered to everyone at the point of referral, not to those already on the waiting list for elective surgery. Prices were fixed through the payment by results tariff system, and providers were expected to compete for patients by offering improved quality. This assumed that both general practitioners and patients would scan data on performance before making their referral decisions.

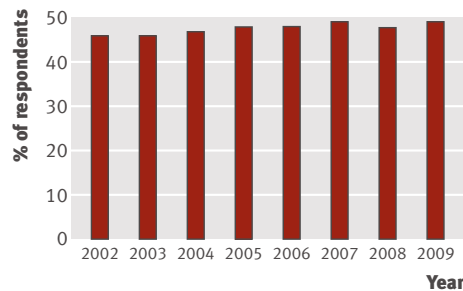
Regular surveys have monitored the scheme since its launch, and these show that patients' awareness of the right to choose and general practitioners' willingness to offer a choice have been slow to grow.<sup>6</sup> Four years after the scheme was supposed to have been implemented nationally, only half of eligible patients were aware that they could choose a provider and less than half of those referred said they had been offered a choice. Recent evidence confirms the impression that most patients are keen on having a choice, even if they choose to remain at their local hospital, but many general practitioners remain ambivalent or antagonistic to the idea.<sup>7</sup>

The offer of choice seems to have intrinsic value to patients, even if they do not intend to switch providers. This is true for a majority of people in all social strata, with older people, people with low educational qualifications, and those of mixed or non-white ethnic backgrounds being especially likely to value choice. Despite a widespread view among general practitioners and hospital managers that choice is relevant only in urban centres, a King's Fund study found that patients living in rural areas were both more likely to be offered a choice and more likely to choose to travel to a non-local provider.<sup>7</sup>

### Informed choice?

In theory, choice should drive quality improvements if providers have a financial incentive to attract patients and patients make use of reliable performance data to inform their decisions. The government in England has promised "an NHS information revolution," with the publication of more detailed information on patients' experience, health outcomes, and safety indicators.<sup>2</sup> In practice, most patients have tended to rely on informal information sources, such as the opinion of their general practitioner, family, and friends or their own experience, with fewer than 1 in 10 looking at officially published data on quality and performance. General practitioners also seem to prefer informal sources, with many indicating a distrust of official performance figures.<sup>7</sup>

Even in the United States, where choice and



Proportion of respondents in NHS inpatient surveys who wanted more involvement in treatment decisions ([www.nhssurveys.org](http://www.nhssurveys.org))

competition have been integral to health care for many years, there is little evidence that patients' choices are influenced by published performance data.<sup>8</sup> Nor is it evident that patient choice itself drives up quality standards, although the perception of competition between hospitals does seem to have had an effect.<sup>9</sup> This finding was reinforced by three recent studies of the effect of the NHS reforms.<sup>10-12</sup> These suggested that certain hospitals in areas where competition is more intense may have succeeded in attracting more patients, reducing preoperative lengths of stay, and reducing mortality, although the mechanisms by which the changes were achieved, and indeed whether there is any causative link between these indicators, remains unclear.

The likely additional effect of allowing patients to choose between consultant led clinical teams is hard to gauge, although it will probably be popular with patients. The government wants other medical specialties to follow the lead set by cardiac surgeons and publish data on outcomes for individual named consultants. Each consultant surgeon's survival rate for heart surgery is currently publicly available on the Care Quality Commission's website (<http://heartsurgery.cqc.org.uk/Survival.aspx>).<sup>13</sup> Publication of these data seems to have led to improved performance with no evidence that surgeons are being more selective about whom they treat.<sup>14</sup> However, it seems likely that the effect of publication on clinical teams, rather than use of the data by patients, has driven the improvements. Since most patients don't seem to use the information to shop around, it is unlikely that the improvements resulted from financial incentives. Professional pride and managerial targets may be the key, stimulated by a desire to maintain parity with benchmarks of best practice.

### Choice of general practice

In March 2010 the Labour government launched a public consultation on extending choice in primary care by removing practice boundaries, with an intention to implement this nationally by April 2011.<sup>15</sup> The coalition government has signalled its intention to proceed with these plans.<sup>2</sup>

NHS patients currently have the right to apply to register with a general practice of their choice, but practices can use their discretion about whether to accept a request. Refusals are usually because the patient lives outside the practice's boundary area or because the practice has reached full capacity. In the new system the practice boundaries will be swept away, allowing patients to register with any practice of their choosing. Some people may want to register with practices near where they work, and some may want to join the lists of more than one practice, but since most patients value continuity and surveys suggest high levels of satisfaction with general practice care, it seems unlikely that many will want to switch.

For some years the Department of Health in England has been encouraging greater diversity and choice in primary care, but the effect of this on quality remains unclear. There are anecdotal accounts of service developments, including increased capacity in "under-doctored" areas, extended opening hours, new forms of provider such as general practitioner led companies and social enterprises, and innovative services such as polyclinics and clinics for specific disadvantaged groups—for example, travellers and homeless people.<sup>16</sup> But it is not clear whether these developments can be reliably attributed to patients exercising choice or to other policy initiatives in play at the same time.

### Choice of treatment

Although many people say they would like to be able to choose who to consult or where and when to be treated, provider choice is not at the top of most patients' priorities.<sup>17-18</sup> Most place greater value on involvement in choosing their treatment or care package. The government's new commitment to shared decision making tackles this directly. Much more is known about the likely effect of this type of choice on patients' experience and outcomes than about choice of provider because it has been extensively researched.

Shared decision making is a process in which patients are encouraged to participate in selecting appropriate treatments or management options. Not being properly informed about their illness and the options for treatment are the most common causes of patient dissatisfaction.<sup>19</sup> Shared decision making is appropriate whenever there is more than one reasonable course of action and no single option is self evidently best for everyone. This situation is common because there are often different ways to treat a health problem, each of which may lead to different outcomes. These are known as "preference sensitive" decisions.<sup>20</sup> In these cases, it is argued, the patient's attitude to the likely benefits and risks should be a key factor in the decision.

The white paper promises patients access to decision aids to support informed choice of treatment.<sup>2</sup> Use of evidence based decision aids has been shown to lead to improvements in patients' knowledge, better understanding of treatment options, more accurate perception of risks, and reduced demand for elective procedures.<sup>21</sup> The idea of shared decision making attracts broad support from patients, professionals, and policy makers, but UK patients rarely get effective support to make decisions.<sup>22</sup> Clinicians have been slow to respond to the evidence that most patients want to participate in decisions about their care, citing concerns about time constraints and doubts about its relevance to their patients.<sup>23</sup> The policy implies a challenge to entrenched attitudes and the need for big change in practice styles.

### Conclusions

Choice has intrinsic value to patients. Most like the idea that they should be offered a choice of provider and, in particular, a choice of treatment. The evidence suggests that both can be beneficial, although there are risks. There are reasons to be concerned about the increasing complexity and fragmentation of healthcare delivery and the potential costs of providing greater diversity and choice. Nevertheless, the genie is out of the bottle and the expectation of choice will not go away. The task now is to develop effective means of engaging patients in healthcare decisions and of monitoring the outcomes.

Importantly, the availability of choice depends on the willingness of clinicians to offer it. They must ensure that patients understand the options and their likely consequences by pointing them to reliable information sources, eliciting their preferences, and facilitating their decisions. The evidence reviewed here suggests a reluctance on the part of general practitioners to play this supporting role, coupled with a gulf between what patients say they want and what general practitioners believe they want. This is worrying because the government's plans assume that general practitioners understand patients' preferences and will commission services accordingly. Implementation of the plans for extending choice will be a major test of the effectiveness of general practitioner led commissioning.

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An international Salzburg global seminar entitled "The greatest untapped resource in healthcare? informing and involving patients in decisions about their medical care" will take place on 12-17 December 2010, in Leopold Schloss, Salzburg, Austria. For more information see <http://www.salzburgglobal.org/>.

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## BMJ BLOGS Vasiliy Vlassov A Russian conference without pharma support



Tatarstan is a national republic in the Russian Federation. It is small by Russian standards (the size of the Netherlands), economically stable, and has an educated population.

Recently a conference took place at the local medical academy entitled QJUM: Quality Information for Quality Use of Medicines.

It would be trivial to write about this conference if it was a normal conference. However, the set up of this conference was rare in Russia: there was no drug industry support and not a single drug or device booth in the foyer.

How is this possible in a country where the government is famous for never supporting the participation of doctors in conferences and for paying them wages that are 25% of the amount that bus drivers receive? In Europe only Russia and Ukraine pay doctors below average wages, and most influential medical academies fill their specialist conferences with industry sponsored symposia, specifically to make money.

The clinical pharmacology professor of the Tatarstan Medical Academy, Lilia Ziganshina, organised the conference. She was heavily influenced by Peter Mansfield and HealthySkepticism.org (previously MaLAM, the Medical Lobby for Appropriate Marketing), and she was serious about moving towards independent drug information that is free from the biases introduced by marketing.

If I had been asked a year ago whether it is possible to arrange a big pharmacology meeting without industry support, I would have said that nobody will do it. It would be like being hungry at a table filled with free snacks. But it happened! We had the first conference of this kind, with no drug advertisements.

Of course, the conference was not perfect—life is not perfect. As well as the support received from educational institutes, it was sponsored by one of the big oil and gas companies and the biggest national publisher of medical books, Geotar.

Although this sponsorship might not be ideal, it represents much less of a conflict of interest than sponsorship from the pharmaceutical industry, which is why this conference was such a special event and worth paying attention to.

Vasiliy Vlassov is a professor of medicine at the Higher School of Economics, Moscow. His research interests are in epidemiology, evaluation of diagnostic tests, public health, and especially delivery of healthcare with scarce resources. He is the co-founder and current president of the Russian Society for Evidence Based Medicine.

**Competing interests:** VV's attendance at the conference was sponsored by Geotar.

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