

MAKING SHARED
DECISION-MAKING A REALITY
No decision about me, without me

Angela Coulter, Alf Collins

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Summary

Shared decision-making is a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a system for recording and implementing patients' informed preferences.

The government wants shared decision-making to become the norm in the NHS, but there is confusion about why it is important, what it involves and what the implications might be for patients, clinicians and the wider health service. This report clarifies the concept and outlines the actions needed to make the aspiration a reality.

Why shared decision-making is important

Shared decision-making is viewed as an ethical imperative by the professional regulatory bodies which expect clinicians to work in partnership with patients, informing and involving them whenever possible. It is important for patients because they want to be more involved than they currently are in making decisions about their own health and health care. There is also compelling evidence that patients who are active participants in managing their health and health care have better outcomes than patients who are passive recipients of care.

Shared decision-making is also important for commissioners because it reduces unwarranted variation in clinical practice. Shared decision-making is the principal mechanism for ensuring that patients get 'the care they need and no less, the care they want, and no more' (Al Mulley, personal communication) and is the essential underpinning for truly patient-centred care delivery.

What shared decision-making involves

There is some confusion about the relationship between shared decision-making, self-management support and personalised care planning. We argue that they are similar philosophies, each requiring that clinicians recognise and respect the patient's role in managing their own health. They also require advanced communication skills and the use of a number of tools and techniques to support information-sharing, risk communication and deliberation about options.

Shared decision-making is appropriate for decisions about whether to:

- undergo a screening or diagnostic test
- undergo a medical or surgical procedure
- participate in a self-management education programme or psychological intervention
- take medication
- attempt a lifestyle change.

What are the implications for patients, clinicians and the NHS?

The key message is that we could, and need to, do better. Effective shared decision-making is not yet the norm and many patients want more information and involvement in decisions about treatment, care or support than they currently experience.

Embedding shared decision-making into systems, processes and workforce attitudes, skills and behaviours is a challenge. Several pilot implementation projects are under way and they will offer valuable experience for practice in the future.

We make a number of suggestions about what needs to happen to make shared decision-making a meaningful reality. These include:

- greater national provision of decision aids and the development of common and consistent approaches
- the identification of decision points in care pathways and the monitoring of the quality of shared decision-making
- better provision, recording of, and support for, shared decision-making by providers
- inclusion of the subject in training; appropriate incentivisation
- the inclusion of shared decision-making in commissioning standards and contracts.

Introduction

The government wants to place patients' needs, wishes and preferences at the heart of clinical decision-making by making shared decision-making the norm throughout the NHS. The Secretary of State for Health, Andrew Lansley, has articulated this vision in the phrase 'nothing about me, without me'. But as yet there has been little guidance on what this means for clinicians, patients, provider organisations or commissioners, or on how the government intends to support its implementation nationally. This report aims to fill that gap by clarifying what shared decision-making is and why it is not yet widely practised, and suggesting what needs to be done to make the aspiration a reality.

This report is concerned with shared decision-making in the context of the decisions made between individual patients and individual clinicians. We are not concerned here with the wider aspects of public involvement; the focus is on patients' engagement in their own health and health care.

We have written this paper with a broad readership in mind, including policy-makers, health care leaders, patient and consumer groups. Each group has an important role to play in supporting the implementation of shared decision-making. We also hope that the paper will be of interest to clinicians, both as commissioners and as providers of health care. Ultimately it is clinicians who need to deliver the vision of shared decision-making – it is only they who can choose whether or not to share decisions with patients.

What is shared decision-making?

Shared decision-making is a process in which clinicians and patients work together to clarify treatment, management or self-management support goals, sharing information about options and preferred outcomes with the aim of reaching mutual agreement on the best course of action. Much of the research evidence about shared decision-making has focused on:

- major health care decisions where there is more than one feasible option
- screening tests and preventive strategies
- self-management support for people with long-term conditions.

However, we think that most consultations between clinicians and patients should evoke the spirit of shared decision-making. We explain this in more detail below.

Shared decision-making explicitly recognises a patient's right to make decisions about their care, ensuring they are fully informed about the options they face. This involves providing them with reliable evidence-based information on the likely benefits and harms of interventions or actions, including any uncertainties and risks, eliciting their preferences and supporting implementation. There are three essential components:

- provision of reliable, balanced, evidence-based information outlining treatment, care or support options, outcomes and uncertainties
- decision support counselling with a clinician or health coach to clarify options and preferences
- a system for recording, communicating and implementing the patient's preferences.

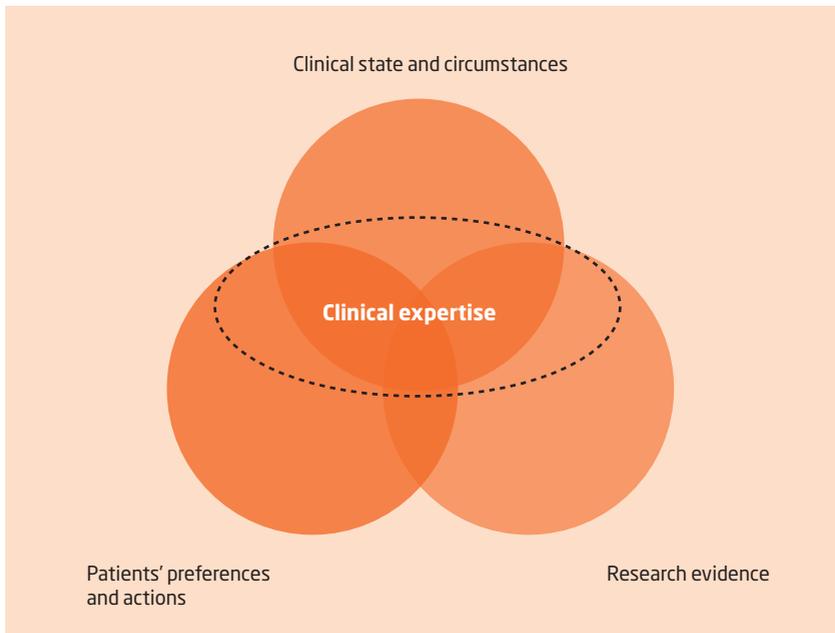
Two sources of expertise

Shared decision-making may involve negotiation and compromise, but at its heart is the recognition that clinicians and patients bring different but equally important forms of expertise to the decision-making process (*see* Table 1).

Table 1 Sharing expertise

Clinician's expertise	Patient's expertise
Diagnosis	Experience of illness
Disease aetiology	Social circumstances
Prognosis	Attitude to risk
Treatment options	Values
Outcome probabilities	Preferences

The clinician's expertise is based on knowledge of the diagnosis, likely prognosis, treatment and support options and the range of possible outcomes based on population data; the patient knows about the impact of the condition on their daily life, and their personal attitude to risk, values and preferences. In shared decision-making the patient's knowledge and preferences are taken into account, alongside the clinician's expertise, and the decisions they reach in agreement with each other are informed by research evidence on effective treatment, care or support strategies (see Figure 1).

Figure 1 An updated model for evidence-based clinical decisions

Reproduced from Haynes *et al* (2002) with permission from BMJ Publishing Group Ltd

For shared decision-making to take place, both parties must commit to sharing information and decision-making responsibility, recognising the need for this and respecting each other's point of view. They should also commit to a documented conversation about risk, which is formalised for surgical procedures by the process of gaining informed consent but is currently less rigorously implemented and documented when the decision concerns medication use or behaviour change.

All of this is in sharp contrast to the traditional approach to clinical decision-making – still prevalent in the NHS – in which clinicians are seen as the only competent decision-makers, with an expectation that they will make decisions *for* rather than *with* patients. Patients rarely challenge this assumption because they defer to the clinician's knowledge, with neither party explicitly acknowledging the legitimacy of the patient's expertise and decision-making role.

Decision aids

It is unusual for there to be a simple choice between undergoing/undertaking a procedure or not. At most decision points there are a number of treatment, care or support possibilities to consider. In many clinical situations, clinical guidelines identify, summarise and evaluate the highest quality evidence in order to support decision-making. Most guidelines aim to support clinicians, not patients, in decision-making.

But if the patient is to play a part in the decision-making process, they need clear, comprehensible information about the condition and the treatment or support options. This must be based on reliable research evidence, outlining outcomes, risks and uncertainties in a clear, comprehensible and unbiased manner. Providing this verbally in a busy clinic can be extremely challenging. One solution is to 'prescribe' a decision aid that the patient can review and absorb at home, before returning to discuss their preferences and decide how to treat or manage their condition. Patient decision aids are similar to clinical guidelines, in that they are based on research evidence, but they are designed not just to inform patients, but to help them think about what the different options might mean for them and to reach an informed preference.

Patient decision aids take a variety of forms, spanning everything from simple one-page sheets outlining the choices, through more detailed leaflets or computer programmes, to DVDs or interactive websites that include filmed interviews with patients and professionals, enabling the viewer to delve into as much or as little detail as they want.

Decision aids are different from more traditional patient information materials because they do not tell people what to do. Instead they set out the facts and help people to deliberate about the options. They usually contain:

- a description of the condition and symptoms
- the likely prognosis with and without treatment
- the treatment and self-management support options and outcome probabilities
- what's known from the evidence and not known (uncertainties)
- illustrations to help people understand what it would be like to experience some of the most frequent side-effects or complications of the treatment options (often using patient interviews)
- a means of helping people clarify their preferences
- references and sources of further information
- the authors' credentials, funding source and declarations of conflict of interest.

There are now a large number of patient decision aids available and many of them are listed on two websites, www.decisionaid.ohri.ca and www.thedecisionaidcollection.nl (see box overleaf). Their use has been evaluated in randomised controlled trials and a Cochrane review has summarised the findings from this body of evidence (O'Connor *et al* 2009). This review of 55 trials found that use of patient decision aids led to:

- greater knowledge
- more accurate risk perceptions
- greater comfort with decisions
- greater participation in decision-making
- fewer people remaining undecided
- no increase in anxiety
- fewer patients choosing major surgery.

Patient decision aids

NHS Direct (www.nhsdirect.nhs.uk) was commissioned by East of England Strategic Health Authority to develop or acquire a range of patient decision aids that could be hosted on its website (Elwyn *et al* 2010). Decision aids for patients with prostate cancer, benign prostatic hyperplasia and knee osteoarthritis are currently available and more are planned. The project is being supported by the Department of Health's Quality, Innovation, Productivity and Prevention programme (QIPP). The project team is working to engage clinical support for the programme and it is hoped that it will prove to be an effective contribution to demand management strategies, reducing unnecessary treatments and increasing efficiency.

Meanwhile NHS Choices, which is funded by the Department of Health, includes detailed information on diseases and treatments on its publicly available website (www.nhs.uk). Several pages now include treatment option tables designed to facilitate shared decision-making. These cover topics such as glue ear, ulcerative colitis, quitting smoking, prostate enlargement, haemorrhoids, high blood pressure, bunions, acne, varicose veins, rosacea, back pain, angina, erectile dysfunction, carpal tunnel syndrome, vitiligo, urinary incontinence and tennis elbow, and more are in the pipeline.

An international group of researchers, clinicians, patients and policy-makers has collaborated on the development of a set of guidelines for assessing the quality of decision aids, setting standards to ensure that they are reliable and unbiased (Elwyn *et al* 2009).

Despite the widespread interest in shared decision-making, use of decision aids in the United Kingdom has been patchy. There are a number of reasons why this may be the case:

- decision aids have not been developed or adapted for use in the United Kingdom
- decision aids have not been well disseminated
- clinical teams don't know about decision aids
- clinical teams are not clear about (or are sceptical of) the evidence to support the use of decision aids or are unclear about their applicability in a UK context (many – though by no means all – decision aids have been developed outside this country)

- clinical teams are uncertain about where decision aids should sit in a care pathway
- clinical teams believe that they don't have the time to use decision aids
- clinical teams haven't been trained in decision support.

The development of a high-quality decision aid is a labour-intensive task that can take many months. It involves consulting patients about their information needs, reviewing, selecting and summarising clinical evidence, script design and development, web development and content management, writing and editing text, filming video clips, field testing with patients and clinicians, and evaluation. A carefully designed dissemination and implementation plan is required, together with resources and processes for regular updating linked to changes in the evidence base and the possibilities of new technology. Most important of all is securing clinical engagement throughout the process to ensure that the decision aids are a credible and useful resource.

The process requires expertise in evidence review, patient and clinician engagement, scriptwriting, design, research and marketing. While small-scale local initiatives can play their part, doing the job well needs a critical mass of expertise with national coverage. In the light of this, we recommend that the Department of Health task a single organisation to:

- commission a suite of high-quality decision aids that are adapted for the United Kingdom
- make these decision aids widely available and where possible embed them in clinical IT and decision support systems
- market them to clinicians directly, as well as to patients, together with information about their effectiveness and how to implement them
- commission the development of training modules for clinicians in the use of decision aids.

Decision support and health coaching

Shared decision-making involves more than just signposting patients to a decision aid. Crucially it also requires clinicians to assess what patients need in order to make a decision, and to provide them with appropriate decision support.

Relevant support can be given in clinical consultations, but it can also be provided outside the consultation by offering counselling provided by trained health coaches. The aim of coaching is to help people to develop the knowledge, skills and confidence to manage their own health and health care (to become 'activated') and to make treatment decisions and/or lifestyle changes accordingly.

Health coaching is a skilled task involving listening, open and closed questioning, support for deliberation and non-directive guiding. It can be provided over the telephone as well as in face-to-face encounters. Most health coaches are nurses who have received training in motivational interviewing (Rollnick *et al* 2008). Others have been trained in decisional support techniques developed at the Ottawa Health Research Institute in Canada (Stacey *et al* 2008).

These skills are not taught routinely in professional courses so staff may require additional training. Providers should ensure that:

- their staff respect patients' autonomy and decision-making roles
- evidence-based patient decision aids are available at each decision point
- self-management support options are available at decision points
- appropriately trained staff provide decision support counselling at key decision points.

Recording and implementing decisions

Once a decision is made it is important to document it in the patient's notes or electronic medical record. If the patient has used a decision aid, it is also helpful to keep a record of this. Specially designed electronic templates could make the task easier. For example, in Yorkshire and the Humber Strategic Health Authority, such templates have been developed as part of the diabetes Year of Care programme to support personalised care planning and to inform commissioning (Department of Health 2009a).

The record of decisions or the care plan should be accessible to patients as well as health professionals and can be used for a number of different purposes:

- as a medicolegal record of the shared decision-making process
- to help co-ordinate care when patients are receiving treatment or support from a range of different professionals or agencies
- as a personally held record that can be continually updated to support behaviour change if the patient decides to undertake a lifestyle or behaviour change
- to inform a larger-scale commissioning strategy.

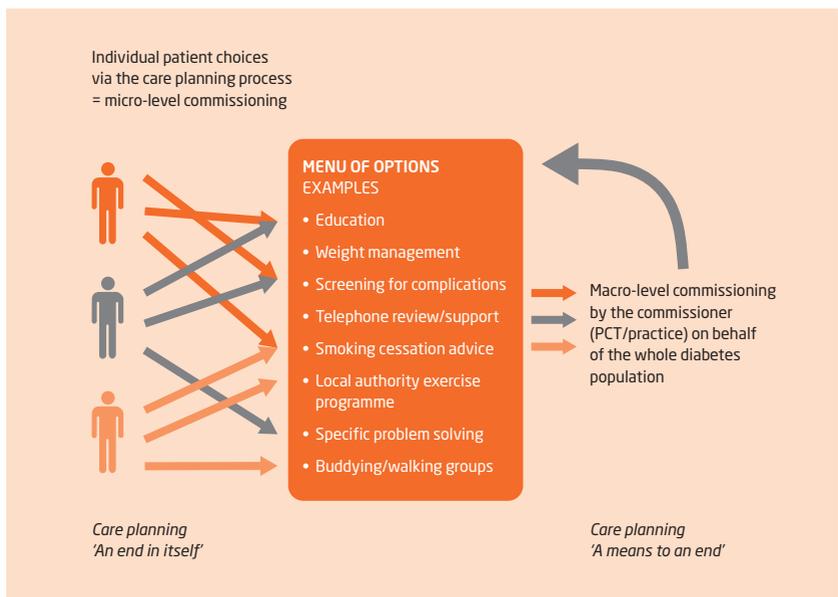
Shared decision-making and commissioning

Commissioners are expected to ensure that health care is distributed appropriately, equitably and efficiently, while remaining responsive to the wishes and concerns of individual patients. The existence of wide variations in rates of

use of common treatments and procedures suggests that this is not currently the case (Appleby *et al* 2011; Right Care 2010).

Shared decision-making can generate valuable information to inform the commissioning process and priorities for future investment. When patients and clinicians work together to plan care through shared decision-making, they soon identify which services are needed and which aren't, and where the gaps are. Every decision made in a care planning conversation is in effect a (micro) commissioning decision. Capturing this information and aggregating it can inform the macro commissioning strategy, ensuring it is truly responsive to perceived needs. A number of national pilot programmes (including the personal budgets pilot programme and the diabetes Year of Care programme) have shown that shared decision-making and care planning can lead to a range of effective, non-traditional services being commissioned, such as cookery classes for people with diabetes (Year of Care programme 2011; see Figure 2 below).

Figure 2 Care planning and commissioning



Reproduced with permission of the Year of Care programme

Shared decision-making might prove to be a better way of managing demand and reducing variations than the referral management schemes that have been established by primary care trusts up and down England, often with little effect

(Imison and Naylor 2010). Currently commissioner-led demand management is struggling to control supplier-induced demand and often losing the battle. If referral management schemes were to incorporate shared decision-making into assessment and triage, supported by patient decision aids and decision support counselling, they might find that more patients would opt for less invasive and less expensive treatments.

This is one of the strongest arguments for engaging clinicians in commissioning – they should be well placed to respond to needs identified through shared decision-making and are therefore ideally placed to commission innovative services.

When is shared decision-making appropriate?

An ethical imperative

The most important reason for practising shared decision-making is that it is the right thing to do. Communication of unbiased and understandable information on treatment or self-management support options, benefits, harms and uncertainties is an ethical imperative and failure to provide this should be taken as evidence of poor quality care.

The Good Medical Council's *Good Medical Practice* guidance for all doctors includes an expectation that shared decision-making will be the norm for most medical decisions. The guidance includes the following statement:

Whatever the context in which medical decisions are made, you must work in partnership with your patients to ensure good care. In so doing, you must listen to patients and respect their views about their health, discuss with patients what their diagnosis, prognosis, treatment and care involve; share with patients the information they want or need in order to make decisions; maximise patients' opportunities, and their ability, to make decisions for themselves; respect patients' decisions.

(General Medical Council 2009).

The other professional regulatory bodies agree with this view, with similar statements appearing in clinical guidelines produced by the Nursing and Midwifery Council (Nursing and Midwifery Council 2008) and the Health Professions Council (Health Professions Council 2008).

All clinicians (doctors, nurses and others) have an ethical duty to inform patients about options and elicit their preferences. Those responsible for undergraduate clinical training, postgraduate training and continuing professional development should develop training modules and assessment methods in decision support and the use of decision aids. Clinicians' skills in decision support should be included in appraisal and revalidation. Patients should challenge clinicians if they are not given opportunities to participate in decisions about their care.

Uncertainty and preference-sensitive conditions

There are no treatments that are 100 per cent reliable and 100 per cent side-effect free and there are very few clinical situations where there is just one course of action that should be followed in all cases. In circumstances where there are a

number of options leading to different outcomes, and the 'right' decision depends on a patient's own particular set of needs and outcome goals, the condition is said to be 'preference sensitive' (Wennberg 2010) (*see box below*).

Preference-sensitive decisions

An otherwise fit 50-year-old man who develops severe knee pain that prevents him from playing cricket presents a different story from an 85-year-old woman with diabetes who has knee pain that prevents her from shopping for herself. Both might have similar degrees of arthritis, but what they want to achieve in their lives and what a knee replacement might offer them will be very different. The philosophy of shared decision-making states that each of these people should make a decision about treatment or support that is *right for them*. We also know that unless they meet a clinician who has been trained in the principles of shared decision-making, this might not necessarily happen (Hawker *et al* 2001).

Shared decision-making for preference-sensitive conditions should be informed by the available evidence and by patients' wishes, needs and preferences. The aim is to ensure that patients are informed about the options and that the treatment or care package that they select supports them to achieve their goals. Inherent in the process is the principle that most clinical knowledge is based on population data and informed by statistical probabilities, so knowledge about risks and outcomes for individuals is always uncertain.

The principle of a shared decision-making conversation is that it should:

- **support** patients to understand and articulate what they want to achieve from the treatment or self-management support options available (their preferred outcome or goal)
- **support** patients to articulate their current understanding of their condition
- **inform** patients about their condition, about the treatment or self-management support options available and the benefits of each
- **support** patients to understand and articulate their own concepts of risk/harm
- **describe** what is known about risks or harm associated with the treatment or self-management support options
- **ensure** that patients and clinicians arrive at a decision based on mutual understanding of this information.

Decision points

The authors believe that shared decision-making is appropriate in every clinical conversation where a decision point has been reached and where the situation is not immediately life-threatening. Patients who present with a life-threatening emergency need an immediate life-saving intervention – a comatose child with injury needs immediate attention, as does a 60-year-old man suffering from a massive heart attack. In these instances, clinicians have a duty of care that they should exercise in order to act in the best interest of patients. Even in life-threatening situations, people who have a terminal disease might make their wishes known in advance (*see* ‘Advance care planning’ below). The extent of engagement in the decision-making process might be different depending on the circumstances and setting, and the patient’s lucidity at the time the decision is taken.

The decision point might be whether or not to:

- undergo a screening or diagnostic test
- undergo a medical or surgical procedure
- undergo another form of intervention, such as a self-management or education programme or a psychological intervention
- take medication (or if in hospital, whether to be given the medication)
- undertake a lifestyle change.

Decision points might occur:

- at the time of a scheduled appointment (*see* personalised care planning)
- at the time of an unscheduled appointment in clinic (either urgent or non-urgent)
- on a hospital ward
- in the accident and emergency department
- in people’s homes.

At the time of such a decision point, there is always a choice between undergoing the procedure or not, or (more commonly) a choice between different options; for example, undergoing a procedure, taking medication, receiving self-management support, or undergoing a change in care provision. Shared decisions can result in a course of action for which the patient needs to take sole responsibility (taking a course of medication at home, for example). In this case, patients are more likely to pursue that course of action if they have made the decision for themselves

(having been supported in the process of decision-making by their clinician or clinical team).

So, there are some important distinctions.

- **Shared decisions about undergoing medical or surgical procedures** are episodic decisions made at a specific point in time. Once the patient and clinician have decided to proceed with a surgical procedure, for instance, it is up to the clinical team to implement the decision to the best of their ability. The patient delegates responsibility for acting on the decision and for risk management to the clinical team. The act of gaining informed consent formalises this process.
- **A decision about medicine-taking at home** is an example of a decision where the clinician supports the patient to decide whether or not they want to embark on a particular course of action. Adhering to the medication (often for a protracted course of time) means that patients need to take responsibility for acting on the original decision on a day-to-day basis. In other words, the original shared decision-making consultation should support patients to work out their own adherence strategy. In addition, patients should understand that in taking a prolonged course of medication, they also take responsibility for the risks, though it is the clinician's responsibility to ensure that they understand the risks when they make the original decision to take medication.
- **Decisions about lifestyle or behaviour change** that people might make in order to manage their own health, are decisions that only they can make because the responsibility for undertaking that change (for converting intention to action) is entirely theirs. Because behaviour change depends on the development of new knowledge and skills and also on the development of confidence that comes through practising new behaviours, change usually happens over time. In order for people to become confident self-managers, they need support while undertaking change and a key component of that support is that they are encouraged to become confident, autonomous decision-makers.

Applying shared decision-making in different clinical settings

We have argued that shared decision-making is relevant in many clinical situations. These include major treatment decisions, managing chronic conditions, modifying treatment plans in hospital, prescribing medicines, undergoing screening or diagnostic tests and advance care planning. The following examples serve to illustrate the relevance and importance of shared decision-making.

Major treatment decisions

Much research in shared decision-making comes from situations where patients are faced with major treatment decisions. Many common conditions can be treated in different ways, with therapeutically similar results. For example, breast cancer can be treated by mastectomy or by breast conserving surgery, resulting in similar survival rates but significant differences in cosmetic outcome and a slight difference in the risk of recurrence. The balance of benefits and risks is such that what is acceptable to one patient may be rejected by another, so the choice of treatment ought to be based on the patient's values or preferences.

Similarly, people with lower urinary tract symptoms caused by benign prostatic hyperplasia can be treated by surgery, drug therapy or active surveillance. Surgery is the most effective treatment, but it also carries the greatest risk of harmful side-effects. The 'best' treatment for the individual depends on how they value particular outcomes balanced against the risk of harm (*see* box below).

Treating prostate problems

In 2003, a group of urologists in England began a pilot programme to implement shared decision-making in NHS trusts (Archer and Finn 2011). Five urology departments implemented decision aids (DVD and booklet) in prostate cancer and benign prostatic hyperplasia (developed by the Foundation for Informed Medical Decision-making in the United States) with their patients. Training in decision coaching was arranged for specialist urology nurses and a decision quality assessment questionnaire was developed for use as a 'feed-forward' tool to check patients' knowledge, values and initial treatment preferences. The decision aids were integrated into different clinical pathways in the five sites with minimal disruption.

The nursing staff valued being able to give good-quality audio-visual information to their patients. Most patients responded very positively to the information package, although a few were confused about whether the treatment options outlined related to England or were only available in the United States. Clinicians involved in the pilot felt the United States decision aids required adaptation to make them more culturally appropriate for the English context. After a great deal of work to build consensus among clinicians and patient representatives, the content of the booklet was redrafted and a film company was commissioned to produce new DVDs. Revised versions of the DVDs and booklets were finally published in 2009, and in 2010 web versions were developed for distribution via the website of NHS Direct. The third phase of the project involved encouraging the use of the redesigned materials in all urology departments in England.

Sometimes the decision hinges on whether or not to undergo a highly invasive treatment, often depending on the patient’s response to pain and disability. For example, patients considering hip or knee replacement to manage the pain of osteoarthritis have to weigh up the potential benefits of surgical treatment against the inconvenience of a long recovery time and uncertain outcome.

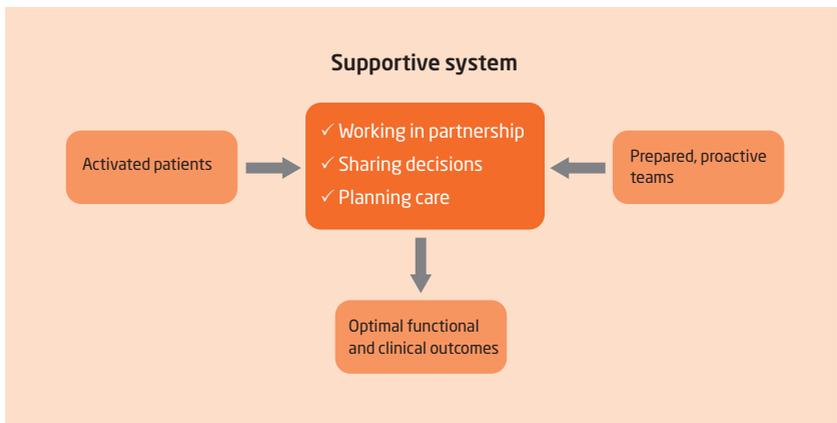
In each of these cases, it makes no sense for clinicians to decide on the treatment without involving the patient. Indeed, the validity of ‘informed’ consent could be called into question if patients haven’t had an opportunity to review all feasible options and express their preferences.

Additionally there may be benefits for the health economy if patients share in decisions about major interventions. The evidence shows that if patients do share in decisions about invasive treatments, their wish to proceed with an intervention is often lower than comparable groups who have not shared in a decision (O’Connor *et al* 2009). It is important however to note that this evidence comes from trial data and may not be reproducible when scaled up to the level of a local, regional or national health system.

Personalised care planning

Personalised care planning is another form of shared decision-making. In this case people who live with long-term conditions are offered scheduled appointments to discuss the treatment, care or support they want in order to optimally manage their own health in between the appointments. The principle behind personalised care planning is that people who live with long-term conditions are responsible for managing their own health on a day-to-day basis, so they should be supported to develop confidence in fulfilling their role as a self-manager.

Figure 3 The chronic care model and personalised care planning



The chronic care model (Wagner *et al* 1996) describes an ideal system to support personalised care planning with people who live with long-term conditions. In the model, the meeting with the clinical team to plan treatment, care or support should be a 'productive interaction' (see Figure 3, opposite). Ideally, that interaction should take place at a scheduled time and place and should be characterised by a willingness of clinicians and patients to work in partnership and to share decision-making.

Personalised care planning is a delivery mechanism to support people with long-term conditions to manage their own health and to share in decisions about their health care. It aims to support people with long-term conditions to work with clinicians to slow the progress of their condition or symptoms and to manage the challenges of living with their condition(s) on a daily basis; as such, it is a secondary prevention strategy (see box below).

Managing diabetes

The Year of Care for diabetes is a demonstration programme launched in response to a national patient survey that showed that many people with diabetes in England were not actively encouraged to participate in planning or managing their care (Diabetes UK 2010). The programme aims to go further than simply providing education, to actively involve people with diabetes in deciding, agreeing and owning how their diabetes is managed. The idea is to transform the annual review, which often just checks that particular tests have been carried out, into a genuinely collaborative consultation by encouraging patients to share information with their health care team about their concerns, their experience of living with diabetes, and any services or support they might need. Both the patient and the health care team will then jointly agree the priorities or goals and the actions each will take in response to these.

For people at high risk of admission (or re-admission) to hospital, the personalised care planning appointment should anticipate possible future health care needs and should support people to plan accordingly. In this instance of *anticipatory care planning*, the production of a care plan can help with decision-making and care co-ordination.

In care planning appointments, clinicians and patients share information and clinicians encourage patients to express their wishes and preferences in terms of what they want from the health or social care system in order to achieve their goals – what they want to be able to do in their lives outside the consulting rooms (see box overleaf).

Managing angina

The National Refractory Angina Treatment Centre at the Royal Liverpool and Broad Green University Hospital NHS Trust in Liverpool aims to ensure that people with angina are fully involved in decisions about the care, treatment and self-management of angina (www.angina.org). On referral, patients are given an initial consultation lasting up to three hours when two refractory angina specialists (cardiology and pain) explore their understanding of their condition, their lifestyle and values. Over the course of four consecutive weeks the patient and, if desired, their carer, attends four two-hour group sessions to examine in depth the treatment options open to them and lifestyle changes they could make. They are empowered to choose for themselves the options best suited to their circumstances with the aim of maximising their quality of life. The programme has resulted in improved quality of life for the patients and significant cost savings.

Outcomes from care planning appointments could be that patients and clinicians share in a decision about:

- an urgent or scheduled admission for investigation or treatment
- referral to outpatient specialist care for investigation or treatment
- a change in medication
- entry into a self-management programme
- further one-to-one coaching support
- not making any changes.

People might choose further coaching support in order to:

- make lifestyle or behaviour changes
- become more confident decision-makers about possible future diagnostic tests or medical or surgical interventions (decisional coaching).

There are many similarities between these two forms of coaching support and both are derived from motivational interviewing.

- **Lifestyle or behaviour change coaching** supports people with long-term conditions to develop the knowledge, skills and confidence to make daily decisions and to take actions to manage their own health (to become 'activated self-managers'). In this case, the health care professional works as a health coach.

- **Decisional coaching** supports people with long-term conditions to develop the knowledge, skills and confidence to make episodic decisions about managing their own health care (to become ‘activated consumers’). In this case, the health care professional works as a ‘health care navigator’.

Decisions on the hospital ward

The rapidity of clinical change and the number of possible tests or courses of action available often involve multiple decisions for hospital inpatients. People who are in hospital may have clouded consciousness or an impaired ability to make sense of complex information. In these cases clinicians may have to make decisions for them, although it may also be appropriate to involve their family members. Hospital-based clinicians must be sensitive to patients’ clinical condition and the psychological resources that they have at their disposal, but nevertheless they should make every effort to involve inpatients in decisions about their health and health care. Evidence suggests that this can help to improve both patient safety and their experience of care (Weingart *et al* 2011).

It is particularly important to involve patients and/or carers at pivotal times of change, especially:

- when there is a need to modify a treatment plan or try a different medication
- in intensive care units when the clinical condition has deteriorated to such an extent that survival seems unlikely
- when patients with an underlying incurable condition or a terminal illness have a deterioration in their health such that discussions about resuscitation versus withdrawal of treatment are warranted
- when there is a choice between prolonging life-saving treatment or opting for palliative care
- at the time of discharge (*see* box below).

Discharge planning

Discharge planning has often been a matter of telling patients when it is time for them to go home. As we move towards a system of care that aims to reduce re-admissions to hospital, it is important that patients are discharged only when they feel confident to manage their own health at home. Compare the following:

‘We plan to send you home tomorrow.’

with

‘On a scale of 0–10, how confident are you to manage things for yourself if you were to go home tomorrow?’

Decisions about medication use

We know that not everyone who is prescribed medication adheres to the prescription. A recent UK guideline from the National Institute for Health and Clinical Excellence (NICE) (Nunes *et al* 2009) encapsulates the current state of knowledge, telling us that people tend to adhere to a prescribed course of medication if:

- they have shared in a decision about taking the medication (if they have had a ‘concordant’ conversation)
- they have also been supported to plan how they are going to incorporate taking the medication into their everyday routine.

This accords with the principle that taking a new medication is a behaviour change – albeit a relatively straightforward one. The responsibility for taking the medication belongs to the patient. It is the clinician’s responsibility to ensure that patients make an informed decision about whether they want to take the medication and how they are going to take it. Patients and clinicians should also have a documented discussion about risk and risk sharing. This is of particular importance when it comes to patients taking responsibility for self-managing medications that have traditionally been managed by clinicians (warfarin, for example, see Garcia-Alamino *et al* 2010) (*see box below*).

Choosing medicines

Shared decision-making is important for pharmacy practitioners as well as prescribers. Originally established by the Department of Health in 2002, the Medicines Partnership Programme is now hosted by the National Prescribing Centre and located at Keele University. It promotes shared decision-making as an approach to help patients get the most from their medicines. The programme focuses on practical measures to address adherence to treatment, including practice development, training for health care professionals on how to work with patients to support medicine-taking, and research. Since 2007 the National Prescribing Centre has developed a number of decision aids. Decision aids on topics such as hypertension management and type 2 diabetes are available for download at www.keele.ac.uk/pharmacy/general/pds/.

Many patients with long-term conditions have to take several medicines at once. This can involve following complex instructions about when and how to take the medications and sometimes these interact to produce side-effects, leading the patient to discontinue use. It is particularly important that these patients know

what to expect, how to manage any side-effects, and when to seek professional help to review their medication regime.

Decisions about screening or diagnostic tests

Shared decision-making is also relevant in decisions about whether to undergo screening and diagnostic tests. There is a common misconception that screening and early diagnosis is always beneficial, but it can involve risk of harm just like any other medical intervention. For example, men considering whether or not to undergo a prostate specific antigen (PSA) test for prostate cancer need to understand the pros and cons. These include the risk of a false positive result, or correct diagnosis of a slow-developing cancer that would not have caused harm, both of which could lead to unnecessary anxiety and treatment (Evans *et al* 2010).

Screening tests

People might choose to undergo screening tests for a number of reasons, including those who:

- have an increased risk (genetic or otherwise) over and above the population risk of developing a specific condition (eg, people who have a strong family history of breast cancer might choose to undertake regular breast screening)
- want to take steps to prevent the development of a long-term condition (many people over the age of 40 prefer to know their blood pressure and/or their cholesterol level).

The principle of screening is that asymptomatic people undergo diagnostic tests in order to take steps to manage the early signs of disease. The advantage is that early diagnosis can prevent disease progression. The disadvantage is that the range of normality for many screening tests is unknown (indeed, ‘normality’ and ‘pathological’ generally describe probabilities not absolutes) and people might be tempted to undergo unwarranted interventions if they believe that they have a treatable pathology.

For some screening tests, the space that a specific result occupies within the range of normality/pathology can be described with a high degree of accuracy. Blood pressure screening is an example (though the blood pressure figures that we choose to describe as ‘normal’ or ‘pathological’ are artificial cut-offs based on the known risk of the development of complications). For other screening tests, the range of probabilities and the degree of overlap between ‘normal’ and ‘pathological’ is much more uncertain and in some cases unknown.

So it is important that people who are considering screening understand the limits of current knowledge and also understand that much of our knowledge is based on statistical probabilities. Some tests may perform poorly in respect of sensitivity (the proportion of people with the disease who have a positive test result) or

specificity (the proportion of people without the disease who have a negative test result). These concepts are not widely understood and require careful explanation.

Additionally (and prior to undertaking the screening procedure), people should be encouraged to consider what course of action they might take when they know the test result. For example, an 85-year-old man who is considering screening for an aortic aneurysm might not want to undergo the test if he would absolutely not countenance surgery. And a pregnant woman undergoing amniocentesis should consider whether she would terminate the pregnancy if the test result was positive (with the associated uncertainty of what 'positive' means when applied to amniocentesis). It is important therefore that people who are contemplating a screening test share in a decision about whether or not to do so with a trained clinician.

Diagnostic tests

People who undergo diagnostic tests usually do so after providing a clinical history and undergoing an examination. The diagnostic tests are then undertaken in order to:

- confirm a suspected diagnosis

or

- rule out a possible diagnosis.

As with screening tests, it is important that people understand the drawbacks of diagnostic tests. The predictive value of diagnostic tests that are being used to confirm or rule out a suspected diagnosis differs from the predictive value when used as a screening tool for asymptomatic individuals (Gigerenzer *et al* 2008) (*see box below*).

Investigating back pain

A 35-year-old man with acute back pain who doesn't have diagnostic 'red flags' is unlikely to have a pathological cause for his pain that can be determined by an MRI scan. However, the scan is highly likely to show age-related changes of no clinical consequence. A number of national guidelines propose that MRI scans should only be performed if people with back pain present with 'red flag' symptoms (less than 5 per cent of people who attend primary care with back pain), but most large-scale studies show that the take-up of MRI scans by people with back pain is much higher (Savigny *et al* 2009). We speculate that the take-up might well be lower if people with back pain shared in a decision about undergoing an MRI scan in the light of the available evidence.

Advance care planning

Advance care planning with people who have a terminal condition offers them the opportunity to share in decisions about the course of action to be taken at pivotal points in their lives should their condition deteriorate rapidly. For example, a woman with a life-threatening bleed from an oesophageal cancer might not necessarily want to be resuscitated. Given the opportunity to think about it in advance and make plans for her care, she might have chosen to die at home. Advance care planning should always produce a shared record of the conversation – an advance care plan – that should be used to inform decision-making should the patient's condition deteriorate rapidly to the point where they are unable to make a decision for themselves (*see box below*).

Living with dementia

In the United States, short video clips used to facilitate advance care planning helped a group of older people understand what it might be like to live with advanced dementia, making it easier for them to decide whether to opt for life-prolonging treatment or comfort care only (Volandes *et al* 2009). Those people with the lowest levels of health literacy gained most in terms of their understanding of the choices and ability to make decisions that they felt comfortable with (Volandes *et al* 2010).

Similarly, people with serious mental health conditions involving occasional psychotic episodes may wish to specify how they would like to be treated should another serious episode occur.

Wherever possible, carers or next of kin should be involved in discussing and agreeing advance care plans, to increase the likelihood that the person's wishes will be followed.

Shared decision-making is both an ethical imperative and a key aspect of high-quality care. Given the extent of uncertainty about the effectiveness of medical care and the presence of side-effects, there is often more than one possible course of action. In such circumstances the 'right' decision will depend on the patient's preferences as well as clinical evidence as reflected in clinical guidelines. Shared decision-making is therefore appropriate in almost every clinical encounter where a decision point has been reached. It is relevant in a wide range of clinical situations. While shared decision-making is usually thought of in relation to major treatment decisions, it also includes decisions about medication use, screening and diagnostic tests. We have argued that personalised care planning and advance care planning are also forms of shared decision-making. While some aspects may differ, for example, the extent to which the agreed treatment

or action is the responsibility of the clinician or patient to implement, we suggest that common approaches to these different types of shared decision-making are developed. The Department of Health should ensure that teams who are developing national policy that is related to shared decision-making (for example, self-management support, care planning, re-ablement, wellness) work together to co-produce policies and communication strategies that are aligned and consistent.

What does shared decision-making look like?

There is developing consensus about what constitutes ‘ideal’ decision support counselling and a number of different models exist; all drawing on the principles of motivational interviewing.

Shared decision-making conversations should begin by building empathy and trust, should emphasise partnership and support and should make it explicit that there is a decision to be made.

Those conversations that gravitate towards self-management support will tend to draw heavily on behaviour change principles, while those that gravitate towards decisions about possible surgical interventions will tend to focus more on attitudes to uncertainty and risk. There is enormous overlap between shared decision-making to support self-management and shared decision-making regarding a treatment decision, but rather confusingly the competencies are usually taught as separate skillsets. In the ‘real world’, clinicians need to employ the skillsets flexibly (according to patient needs, wishes and preferences) so we have chosen in this section to amalgamate them.

Consulting style

The clinician should adopt a consulting style that is curious, supportive, non-judgemental and that communicates evidence about benefit and risk in an unbiased way.

The consultation should contain the following elements:

- developing empathy and trust
- negotiated agenda-setting and prioritising
- information sharing
- re-attribution (if appropriate)
- communicating and managing risk
- supporting deliberation
- summarising and making the decision
- documenting the decision.

The following sections set out in more practical terms how each of these elements can be approached in practice in the clinical encounter.

Developing empathy and trust

- By asking open-ended questions to invite people to tell their story:
 - ‘Tell me about...’
 - ‘How did your symptoms start?’ invites a different story to ‘when did your symptoms start?’
- Affirmations, normalisation, validation to support patient’s own perspective:
 - ‘It’s natural to feel the way you feel’
 - ‘Many people I meet tell me a similar story’
- Reflections – build empathy and seek clarification
 - ‘So, what I’m getting from our conversation is that you are most interested in _____. Is that correct?’

Negotiated agenda setting and prioritising

Patients should be invited to set their agenda before clinicians set theirs.

For example:

- ‘What do you want to talk about in our time together today?’
- ‘What questions do you have?’
- ‘What concerns do you have?’
- ‘What is it that I need to know so that I can help you reach the best decision?’
- ‘There are other things that I’d like to discuss – is that OK?’

Information sharing

Some patients possess incomplete or incorrect information about their condition. Clinicians should invite patients to tell them what they already know and/or fear about their condition or symptoms. For example:

- ‘What do you understand about your condition?’
- ‘What do you understand about what is happening in your body when you get your symptoms?’

or:

- ‘What have you been told about your condition?’

- ‘What have you been told is happening in your body when you get your symptoms?’
- ‘What concerns or worries do you have about your condition?’

Re-attribution

Patients’ beliefs about the cause of their condition or symptoms may be unhelpful or incorrect (misattributed). Unhelpful beliefs lead to maladaptive behaviours. Health beliefs have been investigated in great detail. The so-called ‘common sense model’ of health beliefs proposes that they tend to influence health behaviours rather more predictably than perceived symptoms across a range of different conditions (Leventhal *et al* 1998). For instance, a significant percentage of people with angina pectoris believe that they have a worn-out heart or that angina is a mini heart attack. These incorrect beliefs tend to predict their behaviours – including health care-seeking behaviours (Hirani and Newman 2005).

It is important that people who have incorrect beliefs are not told that they are ‘wrong’, but are invited to consider an alternative viewpoint. For example:

- ‘Many people who have angina think like that. The evidence is that angina isn’t actually a heart attack. Now I have shared that thought with you, what does that mean for you?’

When clinicians and patients have a shared understanding of the condition and/or the factors that might be contributing to the condition or the symptoms, the conversation can move onto a discussion about treatment, care or self-management support options.

Communicating and managing risk

Engaging patients in shared decision-making requires specific competencies, including knowledge of how to communicate risk effectively and the skills to support patients through a process of deliberation.

Studies have found that doctors, let alone patients, have difficulty understanding probabilities (Gigerenzer *et al* 2008). People often get confused when relative risk is cited rather than absolute risk. An example of this occurred in 1995 when there was extensive media coverage of a study suggesting that low dose hormonal contraceptives carried a two-fold increase in relative risk of thrombosis. Many people misinterpreted this as meaning that women taking these pills were twice as likely to have a thrombosis as those who weren’t. The story led to a rise in unwanted pregnancies and abortions, largely due to the way the results were presented. In fact, the absolute (population-based) increased risk was only 1 in 7,000, a much less alarming figure.

Guidelines for communicating risk effectively include using natural frequencies, population-based rates, symmetric framing (ie. using both positive and negative

examples), individually tailored probabilities, bar graphs and simple heuristics (Akl *et al* 2011; Carling *et al* 2009; Gigerenzer *et al* 2010). These skills should be included in professional training courses. It is hard for clinicians to hold all the facts and figures in their heads about outcome probabilities derived from multiple studies, so well-designed patient decision aids can be a great help (O'Connor *et al* 2009).

Having elicited a general overview of the patient's understanding and concerns, the clinician should offer a conversation about benefit, risks and uncertainty, underlining the principle that much of our knowledge about benefit and risk is based on population data and is indeed uncertain in any individual circumstance. Wherever possible, the conversation should be informed by valid performance data of individual practitioners or services.

We recommend 'Ask, Tell, Ask' as a simple format for relaying complex information in a discrete and digestible way.

Ask: 'I'd like us to consider the possible benefits of the treatment – is that OK?'

Tell: 'As far as the benefits are concerned and based on what we know, about one in three people say that they have a 50 per cent or more improvement in their symptoms as a result of this procedure.'

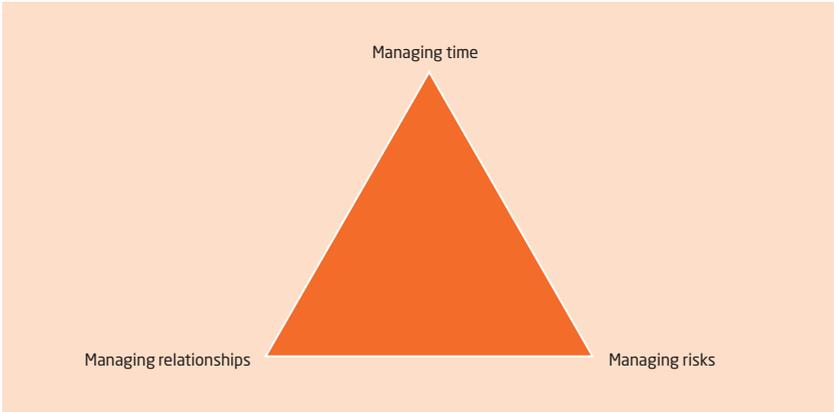
Ask: 'What does that mean for you?'

Note that the last question is open-ended and invites people to reflect on the personal meaning of the statistical statement and to ask further questions if they want to. It is preferable to the more closed 'do you understand?' which does not invite patients to reflect on the personal meaning and does not encourage them to express a preference.

Strategies for managing risk are of particular importance when it comes to clinicians 'trusting' patients to undertake a course of action outside the consulting room (taking medication at home, for example). In this case, it is tempting for clinicians to 'tell' patients what to do in order for the clinician to feel that they are in control of the risk (in this case, the risk of non-adherence). For many clinicians, it is counter-intuitive to support patients to understand and manage risk for themselves, yet this is precisely the approach that supports adherence (Nunes *et al* 2009)

In training programmes clinicians clearly articulate that there is an inherent tension in any consultation between managing relationships with patients, time and risk (*see* Figure 4).

Figure 4 The inherent tension in clinical consultations



Adapted from Howie 2006

We recommend that a shared decision-making conversation that results in patients taking responsibility for a course of action at home (taking a course of medication or putting in place a lifestyle change) formally addresses the issues of risk and responsibility. We also recommend that these issues are also formally documented – preferably in a personalised care plan.

Supporting deliberation

It is important to ask people:

- what they want from the treatment or self-management support options
- what they know about the treatment or self-management support options
- what they know about the benefits of the options available
- what concerns them about the risks of the options available
- what aspects of the treatment benefits or risks are most important for them to consider.

The following prompts can support people to think through their preferences:

- ‘What do you hope you will be able to achieve if the treatment is successful?’
- ‘What do you know about the treatments/care or support that is available?’
- ‘What treatment/care or support options do you want to consider today?’
- ‘What do you know about the benefits of the possible treatments?’
- ‘What concerns or worries do you have about the possible treatments/care/ support options?’

- ‘When it comes to thinking about what the treatment might offer you, or the possible risks of the treatment, what is the most important aspect for us to consider?’
- ‘Here are the options we can talk about _____. Where do you want to start?’

Summarising and making the decision

Clinicians should summarise what they have learned and what the patient has learned, pausing occasionally to verify the summary. Emphasis should be given to those aspects of the conversation where patients have clearly articulated their preferences. For example:

‘In summary, you have back pain and you want to do more walking. We have discussed the various options and your preferences and agreed that what is important for you is a treatment with low risks – you told me that it is really important for you to continue to look after yourself since your wife died.’

‘Given all of this, which treatment should we decide is the right one for you?’

or

‘Given all of this, is there anything else we should consider before coming to a decision?’

A final check:

‘Out of 10, if 0 = no confidence at all, and 10 = supreme confidence, how confident are you that we have come to the right decision?’

‘What led you to say [the number stated]?’

Documenting the decision

There should be a formal system for documenting:

- the decision
- the agreed course of action
- the ongoing roles and responsibilities of each party
- the risk-sharing agreement.

While all of the above is usually formalised in the process of consenting to a medical or surgical intervention, health care providers should ensure that they have documentation systems and processes in place when there has been a shared decision about any other course of action, such as adhering to a medication regime or undertaking a lifestyle or behaviour change. As well as providing a useful record for patients and other professionals they may encounter during

their care, this practice could provide protection from legal challenge if clinicians can demonstrate that patients were offered choices and provided with reliable information about the options.

Working with patients who have low confidence to engage

Many patients have low levels of confidence to engage in shared decision-making. It is not uncommon for patients to say to clinicians: 'please make the decision for me'. The temptation for clinicians (especially in a busy clinic) is to do just that.

We also know that patients can be encouraged and supported to become active partners (Hibbard *et al* 2009). The above framework can help, but what if patients remain passive in a consultation, despite using many of the skills outlined?

The clinician needs to:

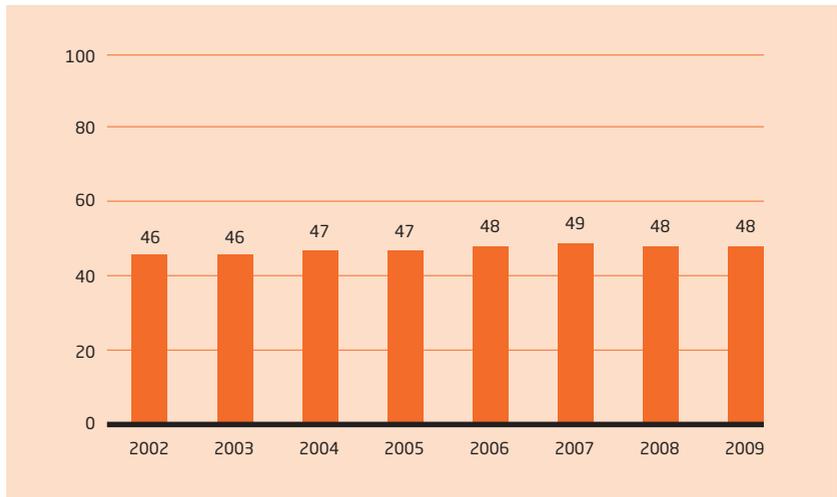
- support patients to understand that clinicians need patients to work with them
- encourage patients to engage with their own ideas, thoughts and concerns.

Shared decision-making as described here requires a change in the behaviour and consulting style of clinicians. The next section considers why shared decision-making is not routinely embedded in clinical practice in the NHS in England and seeks to identify how these might be tackled.

Why is shared decision-making not yet the norm?

Despite widespread support for involving patients in decisions about their care, including a commitment in the NHS Constitution (Department of Health 2009b), shared decision-making is not yet the norm. National patient surveys suggest that at least half of those who experienced a hospital episode would have liked more involvement in decisions about their care and the trend shows no improvement over the last 10 years or so (see Figure 5).

Figure 5 Proportion of inpatients who wanted more involvement in treatment decisions



Source: Care Quality Commission 2010

The practical utility of such survey questions can be called into question, as the question ‘Were you involved in decisions as much as you would like?’ is clearly open to interpretation and bias. Nevertheless, international surveys by the Commonwealth Fund suggest that service delivery is more paternalistic in the United Kingdom than in other European and North American countries, with less involvement in decisions and less support for self-care and self-management (Davis *et al* 2010).

A number of studies have investigated clinicians' attitudes towards sharing decisions with patients in an attempt to understand why it is not yet practised universally (Legare *et al* 2008). Some commonly voiced objections are:

- 'We already do it'
- 'Patients don't want it'
- 'Not appropriate for those with low health literacy'
- 'Patients will want inappropriate/expensive treatments'
- 'No time to do it'
- 'It's irrelevant and ineffective'
- 'There's no incentive to do it.'

We will now examine each of these objections to consider how far they are supported by the evidence.

Patchy implementation

Studies reveal that doctors, nurses and other clinicians often think they are sharing decisions more than their patients do (Stevenson *et al* 2000). While almost everyone agrees that patients should be asked to give their consent before receiving invasive treatment, this does not mean they are always given full information about the alternatives and encouraged to express their preferences.

Informed consent often involves the provision of only basic information about a single treatment, before obtaining the patient's signature on a form to indicate their agreement. Some people have argued that the whole notion of informed consent is much too passive and should be done away with altogether, to be replaced with the principle of informed choice, or shared decision-making (Veatch 2009).

Surveys suggest that only a minority of patients facing major medical decisions are fully informed about the key facts that might influence their treatment choices, and attempts to elicit their informed preferences are relatively rare (Coulter 2010; Fagerlin *et al* 2010; Zikmund-Fisher *et al* 2010). This is largely because doctors have traditionally assumed the role of decision-maker, acting as the patient's agent to determine the most appropriate course of action.

Patients want involvement

Almost everyone wants clinicians to listen, explain and answer their questions (Coulter and Magee 2003). There is also compelling evidence that patients want to be treated as a whole person and that they want to work with clinicians whom

they trust (Ridd *et al* 2009). There is a great thirst for information about diseases and treatments and most patients want more health information than they are usually given. This includes honest assessments of treatment benefits, risks and side-effects. Many people express disappointment about the lack of opportunities to participate in decisions about their care. While not everyone wants an active role, most surveys suggest that a majority do (Flynn *et al* 2006).

The desire for involvement tends to vary between social groups, with younger and better educated people being more likely to say they want an active role. However, many older people and people from disadvantaged groups do want to play an active role in decisions about their care, and clinicians should encourage people to participate. People who have not been encouraged may assume that their views are unimportant or irrelevant and may not seek to share their views or concerns in the future.

People from disadvantaged groups have most to gain

Several studies have shown that concerns that shared decision-making is only of interest to well-educated middle class people are unjustified. The good news is that it is demonstrably possible to inform and engage patients from all walks of life and educational backgrounds, if they are provided with well-designed information materials and given appropriate decision support by well-trained staff (King *et al* 2011; O'Connor *et al* 2009).

Importantly, we know that people with low health literacy tend to defer to clinicians to make decisions for them and also tend to have less good health outcomes than people who are more actively involved in their health. The temptation for clinicians faced with someone who has little knowledge of health matters and is not confident about asserting their views is to make the decision for them, thus further reinforcing their passive role and the tendency towards poorer health in the long term. The good news is that people can be encouraged and supported to become active partners in care (Hibbard *et al* 2009; Volandes *et al* 2011).

Informed and involved patients demand less, not more

It is often assumed that patients who are well-informed about available treatment or self-management support options will choose the most expensive, but many decision aid trials have found that the opposite is the case. It turns out that patients are often more risk-averse than the clinicians who advise them, so when they are given full information about the benefits and harms of treatment they tend to opt for the least invasive therapy or for self-management support. For example, women referred to hospitals in south-west England facing the choice of whether or not to undergo hysterectomy to treat excessive menstrual bleeding

were much less likely to opt for the procedure after being given a decision aid plus a chance to talk it through with a nurse (Kennedy *et al* 2002). Other trials involving elective surgery have found similar results (O'Connor *et al* 2009).

A meta-analysis of eight trials involving patients facing possible surgical procedures found that rates of surgery were 24 per cent lower among patients who used decision aids (O'Connor and Stacey 2005). Studies from the United States have shown the potential of both community and telephone support. For example, older people attending two seniors' centres in Los Angeles benefited from watching and discussing a video on how to manage their health. Those who attended most often were more actively involved in self-management, taking more exercise and reporting improvements in their quality of life (Frosch *et al* 2010). A US trial of telephone health coaching showed that it could reduce the rate of hospital admissions and health care costs among a large group of people with chronic conditions or conditions that might require elective surgery (Wennberg *et al* 2010). It is not yet known if it would have the same effect in the NHS.

Making time to do it

Another common view is that shared decision-making consultations take longer than consultations where clinicians make the decisions. Individual consultations may indeed take a little longer, but time spent engaging the patient in the decision may reduce the overall time spent dealing with someone who is unsure or unhappy about a decision in which they were not involved (Bekker *et al* 2004). Shared decision-making may involve re-thinking clinical pathway design to incorporate time for information provision and coaching.

Shared decision-making is effective

Evaluations of various forms of shared decision-making show that it can lead to the following benefits:

- improved knowledge and understanding
- more accurate risk perceptions
- greater comfort with decisions
- more participation
- fewer patients choosing major surgery
- better treatment adherence
- improved confidence and coping skills

- improved health behaviours
- more appropriate service use.

(Murray *et al* 2005; O'Connor *et al* 2009; Picker Institute Europe 2010):

The chronic care model is underpinned by a body of evidence showing that self-management support can make a real difference to health outcomes (Bodenheimer *et al* 2002). Information is helpful, particularly if it is personalised, but information alone is not enough. It needs to be supplemented by decision support, personalised care planning and self-management education from well-trained health professionals, as well as social support from family, friends and peers. There is evidence that this can improve people's understanding and level of participation, as well as their coping skills and confidence to self-manage, leading to better health outcomes (Coulter and Ellins 2007; Loveman *et al* 2008).

Use of evidence-based decision aids for patients has been shown to lead to improvements in knowledge, better understanding of treatment options and more accurate perception of risks (O'Connor *et al* 2009). Decision aids help to increase involvement in decision-making and increase patients' confidence in the process. They also produce a better match between patients' preferences and the treatments chosen, leading to increased satisfaction. There is no evidence that they make patients more anxious.

'Active' patients are better equipped to make informed and personally-relevant decisions about their care; they tend to make healthier lifestyle choices; they are more likely to adhere to treatment recommendations; they are better at self-managing chronic conditions; and they often use less health care (Mosen *et al* 2007). People with lower levels of activation tend to defer to clinicians as decision-makers, and without active encouragement or support from clinicians often remain at low levels of activation.

Incentives to improve clinical decision-making

Financial incentives

Well-informed patients often prefer to avoid the most invasive treatments, so encouraging them to participate in decisions can help to ensure they receive only 'the care they need and no less, the care they want, and no more' (Al Mulley, personal communication). In some health systems where clinicians are rewarded for activity, there may be a disincentive to promote shared decision-making, particularly where this results in lower rates of intervention. To the extent that clinicians in the NHS, particularly those working in hospitals, are under pressure as a result of the incentives hospitals face to increase volume and throughput, there may be a disincentive to spend time with patients on considering alternative options, including no treatment or intervention. Those responsible for clinical pay

and rewards and for designing future tariffs and payment systems need to ensure they provide incentives for organisations and clinicians to engage patients in shared decision-making.

Monitoring performance

Incentivising shared decision-making will also require appropriate performance measures and feedback so that progress can be monitored. Building on the dictum that 'what gets measured gets done', what is needed is a way of measuring the quality of the decision-making process (Sepucha *et al* 2004). Decision quality refers to the extent to which treatment or management decisions reflect the considered preferences of well-informed patients and are implemented. The key questions are:

- how informed was the patient about the key things a person should know before embarking on a particular treatment, screening test, behaviour change or self-management programme?
- to what extent was the decision personalised to reflect the patient's goals? Did the treatment selected match their preferences?
- did the clinician give serious attention to informing and involving the patient in the decision process?

Specific questions have been developed for use in patient surveys to measure performance in relation to these topics (Sepucha *et al* 2008). These include how well the facts have been communicated (for example information about the natural history of the disease, the treatment options, the benefits and harms of each of these, and the urgency of treatment), and whether the patient's goals have been elicited (for example, the desire for symptom relief, the avoidance of harm resulting from treatment, and attitudes towards the treatment or recovery).

Another way to measure people's capability to manage their own health and health care is to use the patient activation measure (PAM), a tool for measuring people's level of activation. Patient activation involves four stages:

- believing the patient role is important
- having the confidence and knowledge necessary to take action
- actually taking action to maintain and improve one's health
- staying the course even under stress (Hibbard *et al* 2004).

Patients with high PAM scores are better at self-managing their health than those with low scores and achieve better health outcomes (Mosen *et al* 2007).

The PAM survey has also been used with UK populations. One survey of people aged 45 and over, many of whom had long-term conditions, found that only

22 per cent were confident that they could manage their health effectively at times of stress (Ellins and Coulter 2005).

A survey of clinicians based in the United Kingdom and the United States found that many were unwilling to support patient activation (Hibbard *et al* 2010). They were much more likely to say that patients should follow medical advice than that they should be supported to make independent judgements or take independent actions. The good news is that it appears possible to intervene to improve people's ability to manage their health by carefully targeting interventions to their activation level, increasing the likelihood of better health outcomes (Hibbard *et al* 2009).

Both decision quality measures and activation measures can be used to check whether an intervention to promote shared decision-making has been successful. People's ability to manage their health is not fixed. It is possible to intervene to improve it by carefully targeting interventions to their activation level, increasing the likelihood of better health outcomes (Hibbard *et al* 2009).

The NHS Commissioning Board, NICE and local commissioners need to ensure that commissioning standards and contracts identify decision points in care pathways and monitor the quality of shared decision-making within services and pathways by using appropriate patient-reported metrics in patient surveys.

Conclusion

The key message is that we could do better and we need to do better. Effective shared decision-making is not yet the norm and many patients want more information and involvement in decisions about treatment, care or support than they currently experience.

The biggest challenge now is to devise effective ways for supporting shared decision-making and ensuring it is embedded in mainstream clinical practice. Embedding shared decision-making into systems, processes and workforce attitudes, skills and behaviours is a challenge, but several pilot implementation projects are under way and they will offer valuable experience on which to base practice in the future (*see box below*).

Tackling implementation

The Health Foundation, an independent charity, is sponsoring several projects in this field including Co-creating Health, which aims to make self-management support the norm for people with long-term conditions, Making Good Decisions In Collaboration (MAGIC), which is exploring how shared decision-making can be embedded into mainstream clinical practice, and Closing the Gap, which aims to change the relationships between people and health services (*see www.health.org.uk*).

Co-creating Health is focused on supporting people with long-term conditions to develop knowledge, skills and confidence in managing their own health. The programme trains health professionals to support people to self-manage, and is re-designing the delivery of care to enhance self-management support. MAGIC is designing and testing various innovations to encourage the use of shared decision-making. Various demonstration sites around the United Kingdom have been given funds to pilot new and better co-ordinated ways of engaging patients in their own care. All projects are being evaluated in the hope that learning from their experience can be widely disseminated.

It is important that the lessons about how to design systems of care that promote shared decision-making from these demonstration projects are captured and used to inform future policy and practice. It is likely that embedding shared decision-making will require a combination of effective clinical leadership, social marketing, incentives, practical support, education and training, measurement and feedback, and patient push.

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