



# Shared decision making

## A summary of learning from the event

3 November 2011

A Royal College of Physicians event developed in partnership  
with The Health Foundation and The King's Fund



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## Forward

Shared decision making with patients is part of the current NHS policy context ‘no decision about me without me’.

*Clinicians hold the relevant clinical knowledge, apply it to their patients and make recommendations, which, more usually than not, are taken up. While this approach might be acceptable in many conditions for which there is a best choice of care, when it comes to illnesses for which several equally valid treatment options exist, patient preferences should prevail.*<sup>1</sup>

Shared decision making supports self management by patients of their health and to make necessary lifestyle changes to improve health.

The Royal College of Physicians (RCP) is committed to promoting the highest standards of care for patients. Better involvement of patients in their own care, and promoting better patient experience is part of the RCP document *A strategy for quality*.<sup>2</sup> This is set in the context of modern professionalism.<sup>3 4</sup>

We have an active Patient and Carers Network and a college officer for Patient Involvement. We want to build on this work, to engage the RCP members and fellows in developing their thinking and skills to better involve patients in decisions about their own care.

The Royal College of Physicians is pleased to work in partnership with the King’s Fund and the Health Foundation on this agenda. The workshop report that follows sets the current context and lays the foundation for future work by the RCP in this area. We are committed to improving communication between doctors and patients, to enable the best possible outcomes. We will take the insights gained from this workshop and develop further work with the specialist societies and within the RCP to embed the approach of shared decision making.

Dr Linda Patterson OBE

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<sup>1</sup> Lancet, March 2011

<sup>2</sup> [www.rcplondon.ac.uk/policy/improving-healthcare/rcp-strategy-for-quality](http://www.rcplondon.ac.uk/policy/improving-healthcare/rcp-strategy-for-quality)

<sup>3</sup> Future Physician, ISBN 978-1-86016-378-4

<sup>4</sup> Doctors in Society, ISBN 1 86016 255 X

## 1: Introduction

On 3 November 2011, the Royal College of Physicians hosted a workshop to explore issues surrounding shared decision making (SDM) in clinical practice. This document captures some of the learning from the event and outlines key themes discussed and debated on the day.

The workshop was planned in partnership with the Health Foundation and The King's Fund. We invited key theoreticians in the field of shared decision making, and leaders in national programmes delivering partnership approaches to care, plus representatives from the medical royal colleges and specialist societies, to explore what this means both for patients, and for clinicians and their practice.

Linda Patterson, Clinical Vice President of the Royal College of Physicians opened the day.

*The objectives of this workshop are to engage with colleagues and to start thinking through what these concepts mean in practice for us. We want to share experiences and learning, build on good practice, and as a group, get your input on where to go next.*

Short presentations were then given by key speakers. Highlights from their presentations are provided below.

## 2: Professional perspectives: what is shared decision making?

### Jeremy Taylor

*Chief Executive, National Voices, and co-chair of the information workstream of the NHS Future Forum*  
'No decision about me without me' is not a new idea. Putting patients at the heart of health services has been echoed in national policy legislation throughout the last decade. Everyone is paying lip service to the idea, but do we really 'get it?' What do we actually mean by words like engagement and personalisation? There's a lot of jargon, but not a lot of clarity.


Some of the different ways we can think of patients:

- **As a person** –not just body parts to be operated on. Patients want to be well, to be treated with dignity, empathy and receive integrated care. However the NHS still runs on a mainly biomedical model, which makes it harder to treat the whole person.
- **As an entitled citizen** – Patients have rights, as outlined in the NHS constitution. Fair and equal access is hugely important to patients, and is a human rights issue, but isn't really on the agenda.
- **As a consumer** –Healthcare is not shopping, but people do want choice and a responsive system. Are we really listening and responding to our customers in the same way that other industries do? A focus on customer care would probably also improve quality and safety.
- **As an active citizen** – patients want education and support for self care. We are still looking for a credible way to deliver this in the long term.
- **As a partner** – patients want to be involved in decisions about their care. We don't currently do this effectively, and this has clinical, legal, moral and economic consequences.
- **As a commissioner** – People want independence and control and patients like the idea of personal budgets. Some want to take decisions, not share them.

Every patient has all these identities, and everyone wants something different. Our focus must be on responding to people's individual needs and circumstances.

### Angela Coulter

*Director of Global Initiatives at the Foundation for Informed Medical Decision Making, Senior Research Scientist in the Department of Public Health, University of Oxford, and Visiting Senior Fellow, The King's Fund*



Poor quality decisions get made when the patient is unaware of all the treatment options and the clinician doesn't know enough about the patient's personal circumstances. We need to acknowledge that while the clinician has expertise in diagnosis, prognosis treatment options and outcome probabilities, only the patient knows about their own circumstances, values and attitudes to risk. Good decision making brings both sets of expertise together. 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.

This is appropriate whenever people face major healthcare decisions where there is more than one feasible option, but also for people with chronic conditions who want to be involved in planning their care, adopting healthier lifestyles, and enhancing their ability to self-manage.

The core components of SDM are:

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

Decision aids take many forms and are designed to answer the questions often posed by patients. They are often computer based (and many are available online) or can be DVDs with accompanying booklets or simple leaflets.

A Cochrane review, updated in 2011, showed that in 86 trials, the use of decision aids led to greater knowledge and more accurate risk perceptions in patients. There was more participation in decision making, with fewer people remaining undecided. It also appeared to reduce the number of people choosing expensive treatment options like major surgery – potentially reducing the cost of care. However, shared decision making is not happening in the NHS nearly enough. Data from national inpatient surveys showed that nearly half of patients are currently dissatisfied with their level of involvement in treatment decisions. This figure hasn't really changed over the last ten years.

So what are the major barriers?

- **Limited time and resources** – however while it does take some initial investment, there is evidence that SDM saves time in the long term.
- **Inflexible systems** – we need to make a concerted effort to change this.
- **Clinical culture** – we need to get past the underlying belief that clinicians are the experts and patients aren't capable.


If we do succeed in overcoming the barriers, there will be many rewards. Consultations will be better, patients will have improved health literacy and will make more appropriate decisions. This will make care safer, reduce costs and litigation and ensure greater compliance with ethical standards. It will also lead to better health outcomes for patients.

## Dr Alf Collins

*National Clinical Lead of The Health Foundation's Co-creating Health Programme and Clinical Lead of the Somerset Community Pain Management Service*

*15-18 years ago, I was influenced by a friend, Bob Lewin. He invited patients who were on a two year waiting list for cardiac operations for stable angina to come along for an information session to find out more about their condition and their options. Lewin found that many had wanted the operation due to fear. Every time they had an attack of angina they thought they were having a heart attack. Following this simple session to provide more information about their condition, 50% of the patients decided they no longer wanted to have the operation. He demonstrated how a simple shared decision making intervention could have a big impact.*

A person living with a long term condition spends on average 3 hours per year with a clinician. The remaining 8,757 hours per year they are in charge of their own care. So the majority of care for people



with long term conditions is self care. They are the ultimate decision makers and risk takers for their health.

So it's the responsibility of the NHS and clinicians to ensure that people can make informed decisions by providing scheduled follow ups and motivational support. The evidence shows that reactive appointments follow a biomedical model. Scheduled appointments allow people to self manage.

The overall markers of success:

- Activated patients
- Working in partnership with prepared and trained clinical teams in a supportive system.
- To proactively manage health and to anticipate and plan for times of need (care planning).

Our big concern is how we can do this systematically and reliably. That's the aim of the long term conditions QIPP programme.

By case managing those identified at high risk and supporting people to self manage further down the health needs 'triangle' we think we can bring about a 20% reduction in unscheduled admissions. In Kent we have already seen a 40% reduction.

For this we need activated patients. What does 'activation' mean?

- Understanding that you have a role in managing your own health.
- Having the knowledge, skills and confidence to fulfil that role.

It's our premise that it's the health service's job to equip and support people on their journey of activation. This is a new role for clinical teams.

- To act as health partners, healthcare navigators, co-ordinators and coaches.
- Supporting self management- autonomy, decision making and problem solving.

## Dr Steve Laitner

*GP and National Clinical Lead for Shared Decision Making, QIPP, Department of Health*

There is an absolute clinical need for shared decision making. It's not just a fluffy add-on for patient experience. It's a core clinician skill which helps to avoid clinical error where we make the wrong decisions for patients.

*Even as a doctor myself, during my own recent experience of illness I had to fight really hard to get information about my treatment and was not consulted about my care options.*

In renal care, for example, patients are often not offered a choice about whether to have dialysis. This results in a patchwork quilt of variation across the UK, driven not by patient preference but by differing clinician actions. Clinician values are driving clinician decisions, not patient values.

Shared decision making is one of the five streams of the Right Care programme. This has three aims (like a three legged stool it needs all legs to stand):

- develop tools
- embed SDM in systems
- make the culture receptive to SDM.

Patient decision aids are self administered tools that prepare patients for making informed decisions about medical test or treatments. They are designed to increase a patient's awareness of expected outcomes and their own personal values. They can help people who are at a decision crossroad.

Right Care has an ambitious roll out programme over the next 24 months. The programme has already commissioned eight decision aids from NHS Direct, which are now available on the NHS Direct website. There are also video vignettes from therapists and patients.

"Give people the care they need and no less, the care they want and no more" – Al Mulley

### 3: Attitudes, skills, and tools for shared decision making

A number of experiential approaches were used to explore what is needed to routinely embed SDM as part of partnership working between patients and clinicians. On the basis of these it was possible to build up a picture of the core elements that could form the basis of this.

**Clinician attitudes and beliefs:** These were explored using tools developed in the National Diabetes Year of Care Programme that has embedded systematic partnership working with people with diabetes as routine. Participants were given the opportunity to reflect on their individual core attitudes and the impact that these can have on partnership working with patients and SDM. These attitudes were seen as foundational to effective partnership working and SDM.

**Core and advanced consultation skills:** Role-play developed in the Co-Creating Health Programme was used to illustrate the need to for health care professionals to develop and use consultation skills to elicit patient perspectives, and enhance motivation about their condition, so that they are more engaged in decisions about their care. This can change the relationship between clinician and patient from one of power to one of empowerment.

The Making Good Decision in Collaboration MAGIC programme also helps clinicians to build core skills in SDM. This approach divides the consultation into three parts: 'choice talk', 'options talk' and 'preference talk', supported by decision support materials.

**No action as an option:** Adopting the idea that taking no action is also an option for the patient. This often frees patients up from a resistive position and allows them to decide themselves without feeling pressured.

**Use of information in advance:** One of the significant pieces of learning in programmes of partnership working (Diabetes Year of Care and Co-Creating Health) has been the benefit of sharing high quality, personally relevant health information with patients in advance of consultations. This can help patients to understand the issues, options and risks relating to their condition. This changes that 'balance' of consultations and allows individual patients not only an opportunity to understand their condition better and prepare for consultations, but implicit permission to act more as an equal participant in the decision making process. It can also help to make the best use of the consultation time for helpful discussion

**Use of decision aids and prompts within consultations:** One of the MAGIC programme's decision aids was used as part of a role play to illustrate how these can help patients to understand risks and benefits and support choices. Examples of other web based and paper based tools were used throughout the presentations and workshops to show how simple decision aids can help patients choose the best action for their condition by presenting a menu of options accompanied by their potential impact and risk.

**Encouraging patients to participate in decision making:** An illustrative video has been developed by the MAGIC project and runs in patient waiting rooms. It encourages patients to ask three simple questions during their consultation, therefore inviting their involvement in the decision making process.

1. What are my options?
2. What are the benefits and risks of these options and how likely are they?
3. How can we make decisions together that are right for you?

Other decision prompts have been developed in Co-Creating Health and Year of Care around specific conditions.

*"Working in a way that is more shared does take more effort, but you have to try it out properly and openly to see how it works." Dr Dave Thomson*

### 4: Discussion and debate: emerging themes

Lively discussion and debate took place throughout the day. Key themes from this discussion are captured below.



## Patient activation

Ways to activate patients were discussed including the need to harness peer pressure and make good use of social networking, plus providing the right information in advance of consultations so that patients come prepared to enter into a clinical conversation.

Delegates recognised that not all patients will want to take full responsibility for their care, however in some measure most will. Especially with LTCs all, in one way or another, already do, and self manage most of the time more or less successfully. If doctors were better able to support patients to make better lifestyle decisions then they would experience better outcomes. Clinicians therefore have a responsibility to act in a way that will empower patients to make changes, and to change their expectation of the patient-clinician relationship.

*“It can be a challenge to ensure patients are informed and activated, but we have to ensure they are given the opportunity.”*

## Access and equity

There was honest discussion of whether clinicians currently do see patients as experts and as equal partners in their care. “Is there an issue that we as clinicians don’t think patients are up to it?” However there was agreement that as clinicians are currently positioning the more powerful position in consultations and service delivery, it was their responsibility to redress this balance.

There was also discussion around whether all patients are in an equal situation. Some are already disadvantaged due to their social situation or through differences in levels of education. Delegates discussed the ‘inverse care law’, in which the more health needs patients or communities have, the less likely these are to be met. They thought this could be problematic in relation to shared decision making. Use of decision aids for example may be dependent on literacy levels, language skills, dependency or access to a computer. It was agreed that we need to ensure that those who need partnership working the most can access it. The mental capacity act was also discussed, how can SDM work for patients with dementia for example? Some suggested including an assessment of capacity as an extension of SDM.

## Time – needed and saved

The time needed to incorporate shared decision making into consultations was discussed, with some concern that a culture that encourages ten minute appointments is not conducive to more individualised approach to care. It was agreed that while SDM needed an initial investment of time, it would lead to quicker and more effective conversations later in the management process. Furthermore, as patients become more effective at self management, there is likely to be a reduction on the number of appointments. This initial extra time should therefore be seen as an investment which can be ‘cashed in’ at a later date.

## Clinician responsibility

The responsibility of the clinician to ensure the best outcomes for the patient came up repeatedly, both as an area of concern for those who haven’t yet introduced shared decision making, and as a need for culture change. In the current culture clinicians feel responsible for something they cannot do since only the patients themselves can do it. This provokes moral and ethical anxieties if a patient chooses a different option, or refuses treatment. It was felt that there needs to be a culture shift from paternalistic towards partnership, with the clinician’s responsibility increasingly being to make sure that patients are supported to make fully informed and involved choices.

## Providing reliable information

Essential to this is agreeing that clinicians do have responsibility for ensuring patients get the right information. It was acknowledged that patients do already have access to a wide variety of information. Some of this may be unreliable. There is currently a tacit lack of permission to bring that into the room, which means that this can’t be explored with clinicians, and corrected, refined or used. Clinicians however won’t have all of the information patients need all of the time and so have a responsibility for signposting towards reliable sources.



## Education and training needs

The need to train clinicians in the attitudes, approaches and the skills needed for shared decision making was discussed. This needs to be both for the new generation of doctors in training and also for established clinicians. Partnership working and SDM skills need to be part of a clinician's initial and continuing development, topped up regularly and made into an enduring priority. This will also mean educating the clinical teaching faculty. Positive role modelling was seen as critical to embedding this.

## Thoughts on own practice and values

Delegates reflected on how their personal values and motivations influence their decision making in consultations with patients – and there was an awareness of how the patient and clinician can come away with very different perceptions of how a consultation has gone. There was also much positive feedback about the open, facilitative and motivational consultation skills demonstrated during the role play sessions.

*“I used to think I was user-friendly, but scenarios made me think I should rephrase some questions, plus use the pre-consultation information to change culture and make best use of time with the patient.”*

*“The challenge is working with patients differently. I had always thought I was a patient centred clinician but actually we haven't in our training been taught the skills. A psychologist worked with us to teach motivational skills and actually it works so well in getting patients to change their behaviour.”*

## The need for organisational and culture change

Much of the discussion returned to the need for culture change in order to mainstream SDM. From changing the way we think about patients, to creating an environment where clinicians see themselves as responsible for *enabling a shared decision* rather than for *making* the decision – it was agreed there needs to be a move from paternalism to patient centred professionalism.

To do this we need to create a desire to change within organisational structures, systems and processes in the NHS, as well as the skills required for clinical staff to support a more open and equal partnership with patients. Thus SDM will need to happen at all stages of the pathway of care, not just in individual appointments. This means involving all of the staff team, including NHS managers, appointments officers and reception staff to specialist nurses, doctors and allied health professionals in developing SDM in a team setting.

## What haven't we considered?

Some delegates expressed concern that allowing patients to choose will lead to unnecessary and costly interventions which the NHS will have to pay for. However overwhelmingly the evidence, both in experience and from research (in UK and US studies) is, that when given the relevant information, and supported to make decisions for themselves, patients opt for less invasive and expensive interventions, and are keen to make good choices on their own behalf. Overall it appears that costs reduce.

Other concerns raised by delegates included:

- Is there a gap between our headspace and patient reality? How do we know that this is what patients actually want from consultations?
- Proposed changes to the NHS are going to make introducing SDM much harder.
- “Not all the risks and limitations of SDM have been covered today.”
- Sometimes there aren't real options. SDM won't be appropriate for all settings, particularly emergency or intensive care.
- “Having found out what the patient wants, can I legitimise it?”

It was recognised that the workshop was really an early ‘taster’ for SDM and partnership working and these other areas all merit further careful exploration.

## 5: What next?

A number of programmes support shared decision making: Year of Care; CCH; MAGIC; Right Care. But they all have the same objective: to shift attitudes and culture, and to introduce skills, systems and tools that will help transform the dynamic between patient and clinician and deliver more effective care.

### What can the colleges, joint specialist committees and societies do?

*“If leaders in the room feel this should be part of the future then everyone has some responsibility to lead that and take it back. We need to work out where to start as it’s a vast task.”*

A summary of suggestions from the room:

- Developing SDM as an official workstream within the colleges and on specialty committee agendas: There was interest among delegates in developing a group to look at SDM and how to take it forward.
- Education and training – for trainees and established clinicians.
- Exams: Assessment drives learning and Colleges could make sure that exam scenarios include SDM.
- Sharing what we do: Embedding an element of SDM into all the sessions and training days the colleges run on any topic.
- The colleges need to actively influence culture: Should we be seeing SDM and patient empowerment as a driver for efficiency in the system. An investment opportunity.
- Could we mainstream the practice of sending information out to patients in advance of consultations?

*“I will go away from today and re-examine my own practice.”*

*“All clinicians need to look at their own attitudes to working with patients and be willing to build new skills.”*

## 6: Further information

- Kings Fund [www.kingsfund.org.uk/multimedia/angela\\_coulter.html](http://www.kingsfund.org.uk/multimedia/angela_coulter.html)
- Health Foundation [www.health.org.uk/areas-of-work/programmes/shared-decision-making](http://www.health.org.uk/areas-of-work/programmes/shared-decision-making)
- Department of Health [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_074773](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074773)
- NHS Direct [www.nhsdirect.nhs.uk/en/DecisionAids](http://www.nhsdirect.nhs.uk/en/DecisionAids)
- Involvement, decision making and medicines [www.rpharms.com/news-story-downloads/rpsresearchreport.pdf](http://www.rpharms.com/news-story-downloads/rpsresearchreport.pdf)
- *Engaging patients in healthcare*, Angela Coulter, Open University Press 2011
- *Making Shared Decision Making a Reality*, Angela Coulter and Alf Collins, Kings Fund 2011



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